Partnerships for Disability Research in Africa: Lessons Learned in Kinshasa, Democratic Republic of the Congo

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Issues concerning individuals with disabilities are under-researched in Africa, and persons with disabilities remain some of the most highly disadvantaged groups. In an increasing era of globalization, partnerships across borders and boundaries to conduct disability research is inevitable. Yet, such partnerships might be complicated by issues such as unequal power dynamics, poverty, and cultural misunderstandings, among others. In this article, the authors reflect upon their experience partnering for disability research across cultures, with one author being a Congolese person with a disability and the other being a Canadian ally. They discuss the nature of their research relationship, challenges they faced while conducting a seven-month study of personhood and support for people with intellectual disabilities in Kinshasa, and how they addressed these challenges. They also outline lessons learned from this partnership and how their past experience collaborating for disability research will shape their future endeavours.

Keywords: disability research; action research; partnerships

Introduction: North-South Collaboration for Disability Research in Africa

By international estimates, people with disabilities represent 10-15% of the global population (WHO and World Bank, 2011) and there is an enormous need for disability research in the developing world. For example, in recent years, a number of experts have noted the important linkages between disability and poverty (Mitra, Posarac & Vick, 2011; Yeo & Moore, 2003), but others have questioned these conclusions and noted the need for more targeted research in order to draw more concrete conclusions (Eide & Ingstad, 2013). Previously neglected and segregated, people with disabilities have increasingly demanded full inclusion in the community and voice in matters that impact them (Gilbert, 2004). By rejecting the passive role of research subject, people with disabilities can have greater influence over the research that impacts their lives (Kiernan, 1999). Academics and community organizations are also increasingly recognizing the importance and mutual benefits of partnering with people with

disabilities in research that concerns them (Bigby & Frawley, 2010; Condor, Milner & Mirfin-Veitch, 2011). In an increasing era of globalization, international partnerships to conduct disability research are increasingly prevalent. In spite of the generally good intentions of all involved, researchers from the global North and people with disabilities in the global South still may experience clashing agendas and values (Edejer, 1999). For example, North-South partnerships might be complicated by issues such as unequal power dynamics, poverty, and cultural misunderstandings, among others.

Partnerships with people with disabilities in Africa can be particularly complicated. As Mji and colleagues (2011) aptly note, 'given the history of exclusion and oppression of disabled people in Africa, many disability activists are suspicious of and hostile towards the entire research enterprise' (365). More broadly, outside researchers from disciplines in the social sciences and public health in the DRC and elsewhere on the continent often highlight the importance of trust in the data collection process: 'it is not difficult to acquire data, but gaining the trust and respect of local actors that result in quality data takes time' (Thomson, Ansoms & Murison, 2012:2). In a survey of ongoing disability research in southern Africa, other researchers found that the majority of disability researchers surveyed noted that they involved people with disabilities in some aspect of the research process, albeit at different levels (McKenzie et al., 2014). Interestingly, in this same study, researchers noted that there is limited human and financial capacity for local disability service providers to conduct research. Some respondents also noted that there should be a clear distinction between the role of researcher and activist (e.g., the researcher generates knowledge, whereas disabled persons' organizations are advocates for their constituencies) (McKenzie et al., 2014). Another study of disability research in southern Africa found that this research, largely led by international researchers, lacks focus on solutions and does not provide useful material for disability advocacy (Chalklen et al., 2009). It seems fair to conclude that, to overcome distrust grounded in historical marginalization and continued questions of relevancy/use, partnerships among people with disability, their families, and researchers are essential.

Some of the key benefits of using a participatory approach in research include increased relevance of the research, rigour, benefit to researchers in minimizing logistical problems, increased research utilization, and enhanced empowerment (Turnbull et al., 1998; Stack & McDonald, 2014). Some of the challenges of using a participatory approach in research include the increased amount of time required to do the research, increased costs of research, the need for shared control over research, lack of homogeneity in participant needs or interests, complex ethical challenges and power relations, and incompatibility with institutional or research ethics board regulations (Turnbull et al., 1998; Stack & McDonald, 2014).

There are a number of different types of collaboration or ways for stakeholders to get involved in disability research in the global south. Some researchers have noted that the involvement of people with disabilities in research can be measured on a continuum. For

example, in the context of research about families of people with disabilities, Turnbull et al. (1998) note that the participation continuum has six levels, with the lowest level (level one) having families of people with disabilities as research participants, level two with families as advisory board members, level three with families as occasional reviewers and consultants, level four with researchers as leaders and families as ongoing advisors, level five with researchers and families as co-researchers, and level six as families as research leaders and researchers as ongoing advisors (Turnbull et al., 1998). Similarly, McKenzie et al. (2014) more recently note how participation ranges from weak involvement, with people with disabilities used merely as subjects or for consultation in the advanced stages of the research, to strong involvement, with people with disabilities setting the research agenda, conducting the data collection, and disseminating the research. Our work is particularly informed by the framework proposed by Turnbull et al. (1998) for using participatory approaches. After having outlined our level of collaboration, we will return to this framework to evaluate and further understand the nature of our collaboration.

Although acknowledgement of 'strong' participation of people with disabilities is becoming widely accepted, this level of participation is much easier said than done. For example, in discussions on participatory action research in developmental disability, Stack & McDonald (2014) note that many authors use terms for and provide some explanation to suggest their work reflects equal research partnerships, but they then fail to provide evidence that people with developmental disabilities are actually included in key aspects of the research. These authors note that some researchers blur lines between *participatory methods*, which allow community members to provide first-hand accounts of their views and experiences in research (Knox, Mok & Parmenter, 2000; Paiewonsky, 2011), and *participatory approaches*, which involve an equal, mutual sharing of the nature and direction of research (Balcazar et al., 2006).

In this article, we reflect on our experience as people from different cultures, using a moderate level of participation for disability research in Kinshasa, Democratic Republic of the Congo. We will describe our backgrounds and the nature of our partnership. We will highlight the key benefits that we found through our collaboration and discuss some of the strengths inherent in our partnership that made it successful. We will also discuss the key problems that we faced and provide suggestions for other researchers to avoid similar issues in the future. Finally, we discuss how our lessons learned will shape our plans for stronger levels of collaboration and participation in the future.

Kinshasa, Democratic Republic of the Congo

The Democratic Republic of the Congo (DRC) is an African nation characterized by high levels of poverty. It experienced political and economic chaos, with the kleptocratic state

under Mobutu from 1965-1997, and particulary in the 1990s when pillaging and looting in 1991 and 1993 contributed to a substantial decline of the formal economy, growth of the informal sector, and severe declines in GDP per capita (Shapiro, 2014). The DRC has also been host to a lengthy civil war from the late 1990s into the early 2000's. Civil unrest continues today, largely in Eastern portions of the country.

Kinshasa, the capital city of the DRC, is one of the largest cities in sub-Saharan Africa. It has a population that exceeds nine million, and amounts to over 12% of the population of the entire country (De Herdt & Marivoet, 2011). Although there are no specific estimates of disability prevalence in Kinshasa or the DRC, worldwide estimates of 10-15% suggest a prevalence of disability of around 900,000– 1.35 million people in the Congo. Given ongoing political and economic difficulties, people with disabilities and other vulnerable populations receive limited to no social support from the government, and often must rely on non-governmental organizations, churches, family networks, or self-help organizations to meet their daily needs. In spite of the limited governmental support, the disability advocacy movement in Kinshasa is strong, with advocates calling for improved national policies and support for people with disabilities (Aldersey, 2013). It was in this context that the authors of this article came together to collaborate on a research project related to intellectual disability and support. Having located this partnership in Kinshasa, we will now describe our backgrounds and the specifics of how we interacted in partnership for this study.

Nature of the Partnership

The study that formed the basis of our partnership provided the data for the Ph.D. dissertation of the first author. This dissertation, situated in Kinshasa, explored the social personhood of people with intellectual and developmental disabilities (IDD) and the existence and need for support for people with IDD and their families. Although the first author integrated input of people with IDD and their families in the design of the study and had consultation with people with IDD and their families throughout the research process, this study should not be characterized as one using a participatory approach at the highest level of the Turnbull framework. This is because people with IDD and their families were not equal members of the research team and the first author had primary decision-making control. Additionally, although the second author hails from the study culture of study and is a person with a physical disability, she is not representative of the population under study (people with intellectual disabilities and their families). Although she is a strong advocate for the rights of all people with disabilities in the Congo, she therefore could not be viewed as an adequate representative of the study population. Moreover, because this was a dissertation study, the first author and her U.S.-based university advisors determined the conceptualization, implementation and outcomes of the study. Although this study does not represent the highest level of collaboration and participation outlined by Turnbull et al., (1998), our experiences

represent mid-range levels of collaboration and the lessons we have learned, particularly in collaboration across cultures, may be relevant and applicable for other researchers doing similar work.

Background of First Author

I am a Canadian of European descent and have been working in Kinshasa intermittently since 2006, in collaboration with both international and national organizations, in areas related to civic education and at-risk or vulnerable children. I have a Masters in Special Education from a U.S. university and at the time of the research I was pursuing a Ph.D. in Interdisciplinary Studies at the University of Kansas Faculty of Education and working as a research assistant at the Beach Center on Disability. In 2011, I began preliminary research in Kinshasa to determine a topic for my Ph.D. dissertation and make connections with local organizations to help facilitate the research. During this trip, I reached out to Delphine Assumani Wenda, the secretary of an Association of Centers for people with Disabilities (known by its French acronym, ACHAC), who warmly welcomed me and facilitated many interviews and consultations with key individuals in the disability field in Kinshasa. I secured funding to return for 7 months of dissertation field research on personhood and support in intellectual disability, so I contacted Delphine Assumani Wenda again to see if she would be interested in helping to further facilitate the research.

Background of Second Author

I am a Congolese woman with a physical disability, living in Kinshasa. I have worked as secretary of ACHAC since 2004, often on a voluntary basis when there is a lapse of funding at the association. I was one of the first patients of the Centre de Reeducation pour Handicappes Physiques Huileries (CRHP), a major centre for rehabilitation in Kinshasa. This centre facilitated further treatment for me in Europe, and I lived in Switzerland for nine years with host families while I received medical assistance for my physical disability. I returned to Kinshasa to finish my education, and I have a university degree in Social Sciences. In my position at ACHAC, an umbrella organization for centres for people with disabilities in Central Africa, established in the 1970's, I have collaborated with a wide range of stakeholders, from representatives of international organizations, to national organizations, to individuals with disabilities on a number of city-wide and national disability support and advocacy activities.

Nature of the Work

The second author arranged participant observation sites for the first author, and the first author conducted all of the participant observation during the 7-month period. In addition to the first author's field notes, data for this study also came from semi-structured interviews. We conducted most of these interviews together in French, with the first author going through the pre-determined semi-structured interview protocol and the second author facilitating the meeting, providing any necessary Lingala/French translations, and having the opportunity to ask any other key questions at the end of the interview. The focus of the research was to understand the social construction of intellectual disability and identify existing and needed support for families that have a disability in Kinshasa, Democratic Republic of the Congo. To that end, our research was constructed to answer the following questions: (a) How do people with Intellectual Disability (IDD), their families, and other individuals or entities in Kinshasa create meaning about IDD and how does this meaning contribute to the construction of personhood of the individual with IDD?; (b) What support do people with IDD and their families need and/or utilize to navigate daily life in Kinshasa and how do they access such support in the absence of a strong state?; and (c) How does the construction of personhood influence families to search for and secure access to support; and, conversely how does support influence the construction of personhood?

Throughout the data collection process we debriefed with one another formally and informally about what we were seeing and planned our future observation and interviewing efforts strategically and in alignment with emerging themes. We collected data throughout seven months in the field. At the conclusion of data collection we co-presented initial results to a group of study participants and requested oral and written feedback from this group through a final member check. After the seven-month period of data collection, the first author returned to North America to do a final analysis of the data and write her dissertation. We kept in regular contact, and on numerous occasions the first author contacted the second author for questions or requests for further clarification. We have continued our collaboration by co-writing academic articles and working on funding proposals, and holding community information sessions about the results of the study in Kinshasa.

Reflecting on our Collaboration

In the paragraphs that follow, we reflect on the advantages that we gained through collaboration. Next, we note the specific attributes of this collaboration that made it particularly successful. Finally, we highlight our key challenges in conducting this collaborative research.

Advantages of our Collaboration

Our collaboration had many important advantages. These advantages ranged from facilitation of the research logistics, to bidirectional sharing of knowledge, to ensuring the social validity of the research.

Logistics

Perhaps the most tangible advantage of this research collaboration was related to the facilitation of logistics. On the most basic level, having a local researcher who could quickly navigate daily life and the organizational issues of conducting research made it possible to do much more in a shorter amount of time. Partnership with the second author also enabled the first author to obtain more relevant and useful data from a wide and diverse range of stakeholders. Because the second author has a strong and established reputation among people with disabilities and disabled peoples' organizations, she was able to arrange interviews with individuals and create opportunities for participant observation for the first author that she never could have made on her own. This is an important note. Most persons who conduct research in the global south now recognize the importance of having local research facilitators (also known as 'gatekeepers' in ethnography) to limit the required time and effort needed to conduct research.

Yet, when doing disability research, it is not enough to simply have a local person facilitating logistics. Rather, the local person must also be a person with a disability or a person regarded with great respect among the local disability community. Because people with disabilities in developing countries have a history of being subject to abusive, disempowering, or paternalistic practices of colonizers, international aid organizations, and researchers, it is important to demonstrate that research activities are vetted through the community. One important way to do this is to have a person with a disability control the logistical aspects of a research project. Because the second author is an active and well-known advocate for the rights of people with disabilities in Kinshasa, she had the required credibility with the population of study to allow us access for the research.

The advantages that we found in logistical benefits align with the observations in the Turnbull et al. (1998) framework, wherein the researchers note benefits from expanded networks for recruitment, a decrease in time and effort required for many aspects of the network, and improved instruments that result in higher completion rates

Bi-Directional Transfer of Knowledge

Participating in this research provided each of us with rich opportunities for learning. For the

first author, this was the first full study that she had done with people with intellectual disabilities and their families in Kinshasa. Beyond the scientific knowledge gained, collaborating with a local person with a disability provided the first author with invaluable insight about functioning in general in Congolese society (e.g., how to navigate public transportation, how to act respectfully when visiting family homes, expectations about "gifts" and honoraria for services or information in certain circumstances) and navigating relationships within the network of disabled people's organizations in Kinshasa. The latter comprised of organizations that often have divergent and competitive needs and interests. This enabled the first author to gain easier access to respondents, navigate community relationships, and gain the community trust required for the collection of quality data. Beyond this foundational knowledge about Kinshasa society in general and working with people with disabilities in Kinshasa in specific, this collaborative relationship enabled the first author to better understand how to 'do research' in this context. For example, the second author emphasized the importance and logistical/political necessity of often lengthy, pre-project consultation with concerned stakeholders, potential participants, and key authorities before the onset of data collection. The second author also communicated the necessity of respecting hierarchy and authority and obtaining all the relevant official permissions before and during data collection.

For the second author, facilitating this project also provided many new opportunities for learning. For example, prior to participating in this project, the second author had never noticed or reflected on the lack of representation of people with IDD and their interests in her national disability advocacy collaborations. The opportunity to conduct research with people with IDD provided the second author with exposure to a population that had previously had little representation in the decision-making process of Congolese disability advocacy work. Because of the knowledge the second author gained by facilitating this research, she has since made efforts to ensure that people with IDD are represented in her disability advocacy and support work on a city-wide and national level. Moreover, she learned that in addition to people with disabilities themselves, families and those close to individuals with disabilities can provide important perspectives on their experience with disability.

In addition to exposure to the views of a different disability population, this study also provided the second author with experience of a North American research ethics review board. This was an opportunity for the second author to learn about various important procedures such as obtaining informed consent/assent and ensuring that participants do not feel pressured to participate in the research. Finally, by transcribing the audio files of interviews, the second author gained valuable technical skills that she will transfer to other beneficial endeavours.

Development of research capacity and technical skills is a key benefit for a community member to become engaged in research. Although there has been remarkable progress over the past two decades in building research capacity in the developing world, some have noted

that 'research capacity in the South remains one of the world's unmet challenges' (Nchinda, 2002: 9). In sum, this collaboration built the capacity of the first author to function in a Kinshasa society and it strengthened the capacity of the second author to be a partner in research and to have increased exposure to the concerns of a new disability population.

Research Validity

Both authors agree that this partnership was characterized by full collaboration. This collaboration was possible primarily because the first author visited the field one year before her study to understand the situation on the ground. This month-long pre-study trip was essential for early consultations with potential study participants and beneficiaries to identify research questions and choose appropriate methods for answering them. This short pre-study visit also enabled the foreign researcher to identify research partners and to become affiliated with the local partner organization, ACHAC. Being affiliated with an organization was important in a Kinshasa context because generally one cannot conduct valid research if he/she is not affiliated with a structure that is credible and recognized by the government.

This study also benefited from better questionnaire and interview protocol design because the second author enlisted other key stakeholders to review the interview protocol and informed consent form and recommended appropriate changes before we began data collection. Our observation of increased research validity aligns with Seekins & White (2013), who have also noted that engagement and partnership in disability research increases the social validity of a study and has the potential, through research and action, to bring about sustainable positive change. Having outlined the key benefits of our collaboration, we will now reflect on the major reasons why we believe our collaboration was so successful.

Challenges of our Collaboration

Although there were many advantages, this research partnership was not without challenges. The key challenges that we identified revolved around issues with budget, pre-data collection organization and training, and knowledge application.

Budget

One of our key hurdles within our partnership came from discussions of budget. Because this study was funded by a number of small grants for doctoral research, the foreign researcher was limited both in the size of her budget and the items that funding organizations were willing to fund. For example, the bulk of funding received was from dissertation travel grants, which would only fund the researcher's personal travel expenses (e.g., flight, visa

fees, housing allowance) related to the dissertation, and not such items as salaries for other individuals involved in the research. Additionally, because we formalized our research partnership only after securing funding for the dissertation, the second author did not have any involvement in the writing of the dissertation proposal and budget. Rather, the first author created a budget using items and costs in line with university expense standards, research ethics board standards for participant reimbursement, typical Congolese salaries for similar work, and cost of living in the Congo. All of the hurdles we describe below may have been avoided if there had been more communication about funding requirements and budget items before the foreign researcher entered the field and if the local researcher had been actively involved in the proposal-writing and budgeting process.

An important budget item unanticipated by the first author was the second author's need to secure overhead expenses related to the research for her own organization. Because she believed that her organization was integral to the legitimacy of the first author's work, the second author strongly believed that it was important for the project budget to include organizational overheads (to pay rent, water, electricity, and office phone and internet connection) to ensure the longevity of her organization and to compensate it, in addition to compensation for her contribution to the project. This was an initial source of contention that we solved through discussion. Since the research funding was specifically tied to dissertation work, the first author explained that overhead costs were not allowable expenses from the funding agencies, and the second author accepted this. Yet, for partnerships moving forward, we reached an agreement to recognize the importance of local organization overheads and that we would include these in future budget considerations whenever possible. This element of the partnership may never have arisen had the first author initially not taken the time to help the second author understand the nature of the project and discuss allowable expenses under the various funders' regulations.

Another difficulty related to budget had to do with determination of local consultancy fees. The first author created a research facilitator budget item to correspond with the second author's current salary at her organization. Once the first author was in the field, the second author expressed that she did not believe that the budgeted fee was adequate. The topic of local researcher consultancy fee remains an issue of disagreement between us, with the first author leaning more toward the view that consultancy fees should be set in line with existing national standards for similar work and the second author leaning more towards the view that local researchers should be paid a wage similar to that of foreign researchers. To resolve the disagreement at the time, we decided to limit the hours that the second author spent on the project and to pay additional money when the second author accompanied the first author to locations outside of her office (e.g., to participant observation sites on the first day of observation). As we strive to find a middle ground and mutually agreeable solution to discussions of compensation in the future, we plan to consult with international agencies to get an understanding of the consultancy fee range for local people with similar qualifications

and will come to a mutual agreement on fair and appropriate compensation during the proposal-writing process, long before the work is set to begin. This will avoid having discussions or making decisions in circumstances characterized by the pressure of time. This will enable us to find a solution that is equitable and acceptable to both parties.

Pre- Data Collection Organization and Training

Although the first author came for a month to conduct pre-dissertation research, she did not have the foresight to begin training potential future partners in university research ethics review or in research methods at that time. Thus, when she arrived in the field for a second time to begin the actual research, she had to spend significant time training the second author on issues related to reporting to a research ethics review board, informed consent and assent, non-coercive recruitment, and doing research with vulnerable populations (people with intellectual disabilities). Like many others who conduct research with members of the community (Turnbull et al., 1998), the second author and our colleagues in the community found the research ethics review board requirements confusing and cumbersome. Thus, the pre-study steps were a particular hurdle to the smooth functioning of our partnership.

Additionally, we spent valuable field time finalizing the interview questions, the language to secure informed consent and assent, and translating all items from English into French and Lingala. This pre-project communication was particularly difficult because the local researcher did not have reliable or constant access to an internet connection, and, when she did visit an internet cafe, it was at her own expense. Since the research project ended, the local researcher has secured more reliable and near-daily access to an internet connection. To maximize time use and decrease any miscommunications or misunderstandings, we will conduct all pre-data collection tasks for future projects before the foreign researcher enters the field. Additionally, because the Tri-council of Canada provides ethics training in both English and French, all researchers involved in future collaboration, including local partners, will be required to complete this training before the commencement of the project.

Application of Research

Because this research was for a dissertation, the foreign researcher was somewhat constrained by the requirements and expectations of her advisors and Ph.D. program. As such, although we have reported results to the community, we continue to engage with the community to find ways to make these results useful to them. Moreover, we have found that before we can explain the specific results of the research to participants, we have to explain why research is important or relevant for them in their daily lives. We are now committed to take the findings of our initial research and translate them into a convincing argument for public policy change.

Yet, public policy change may take a long time, and we must answer to people with disabilities and their families in the meantime. Because the second author interacts with her colleagues with disabilities and their families in the Congo regularly, she has had to interact more than the first author with people who are anxious to see quick, tangible outputs of their participation in the project.

We are not alone in our concerns about the applicability of our research and our ability to provide answers to the community. Turnbull and colleagues (1998:180) note that when doing research with local, non-academic partners, these partners may 'recognize the extreme shortage of funding for services and wonder about the rationale for spending money on research'. Others agree that one of the challenges of research as a commodity largely contained within academic institutions is to ensure that it remains relevant for its constituency (Mji et al., 2011). Lately, disability research participants have become interested in knowing from researchers how their research outcomes will be used to address their needs and priorities (Priestley et al., 2010).

We have taken the opportunity in our presentations of research results to the community to hold roundtable discussions to help us understand what future research we might conduct that might have more direct applicability in their lives. As we have discovered, people with disabilities and their families in Kinshasa, confront so many problems on a daily basis that engaging in research simply to advance theoretical arguments, such as those related to 'personhood', has little value for them. Although theory is important, when conducting research on disability in the global south, application, or 'action' as a result of the research, is equally crucial. Thus, in the future, we will conceptualize research also in terms of what the research may produce – for example a public policy briefing to be presented to parliament, radio programming to disseminate information about research findings and further resources, and other tangible items that we can leave with the community to hopefully spur further action (e.g., posters, brochures).

All of the challenges that we address here we were able to resolve through open, frank, discussion and communication with one another and with the research participants. This openness and facility in communication is something that we consider a major reason for our success, a topic we will now discuss in further length.

Reasons for Success

Cross-cultural research is often difficult because many of the social, cultural, political, and economic realities of a given context are not openly apparent or discernible for outside researchers looking in. Still there were many important components of our collaboration that made our partnership particularly successful. First, we always made an effort to be open and honest with one another in everything that we did. Moreover, we always endeavoured to keep

in mind that the ultimate goal of the research was to gather information that could also assist others in the future. Keeping in mind our ultimate goal of improving the lives of people with disabilities enabled us to see beyond our personal motivations, and work to constructively resolve any conflict that arose between us for the ultimate benefit of the project. As a further asset to the research and to conflict mitigation, the second author is a strong communicator who consistently discussed and explained the cultural subtleties inherent within our daily activities and observations. Other local partners who are reserved or shy in their interactions or hesitant to share what they believe might be 'unnecessary' details would have been unable to accurately and appropriately communicate critical understandings about life in Kinshasa. The fact that we were both working with an understanding of complete and open communication, we felt comfortable talking to one another about complicated issues or potential cultural misunderstandings/ incompatibilities. This level of openness and communication eliminated many of the potential sources of inter-researcher conflict (e.g., sensitivity, taking offence, or misunderstandings) identified by Turnbull et al. (1998).

Second, within our partnership, we achieved a balance of expertise. We both recognized and respected the strengths that the other brought to the partnership. Although the first author found the funding, initiated the project, and had the research 'expertise', the second author was just as crucial to the project, through her facilitation of participant recruitment, in-depth knowledge of the society, and insightful reflections for data analysis. We both recognized and valued the other's strengths as invaluable to the success of the research. As Turnbull et al. (1998) note, researchers who find themselves in situations of cultural and linguistic diversity must acknowledge the limitations of their own perspectives and be open to diverse points of view. In reflection on her experience in collaborating for disability research, the second author noted that the first author demonstrated an open and receptive attitude towards her, her explanations, and her opinions. She often listened to explanations about the context of the study and followed the second author's advice on research approach. Indeed, the local researcher's ability to explain the context and willingness to express opinions/disagreements alongside the foreign researcher's openness and receptiveness to local explanations and opinions were of utmost importance for a successful North-South research collaboration.

We have interacted with people with disabilities in Kinshasa who assert that they are highly marginalized and that individuals and organizations (both international and national) have used them to advance their own personal/organizational goals (e.g., to raise funds or to garner sympathy). Additionally, local individuals with disabilities have been accused of raising money in the name of groups of disabled persons, but then taking individual profit from those funds, rather than assisting the group. These perceptions and occurrences can result in damaged trust between people with disabilities and organizations that are created to help them. Because of this history, disabled peoples' organizations and individuals with disabilities in Kinshasa can be suspicious of one another and towards outsiders. By demonstrating transparency, discipline and integrity in all of our daily interactions with individuals with all

different forms of disability (physical, sensory, intellectual), and keeping our ultimate goal constant – improving the quality of life of people with disabilities – we were able to gain trust among often distrustful groups.

Finally, the first author saw this project as a particular success largely because of the strong facilitation skills of her local partner. The second author is a highly skilled networker, is never shy to speak her mind, and is open and receptive to dissent, discussion, and learning. When foreign partners are establishing new research partnerships in the global South, it is crucial that they find partners who already possess these important skills, or they foster a culture in the working relationship that encourages and develops the local partner's ability to collaborate in an open and collegial manner.

Plans for Future Collaboration/Suggestions to Others Undertaking Similar Endeavours

In future research endeavours, we will take into account our own lessons learned, specifically: (a) the importance of communication and agreement on the nature of the partnership during the proposal/budget writing process; (b) the necessity to get all pre-study tasks (e.g., consent forms, translations, reaching agreement on study protocol) completed before the foreign researcher enters the field when at all possible; and (c) the need to create research that has direct, tangible, and quick benefits to the community.

To address the latter lesson, we have mutually committed to conducting research using a Participatory Action Research approach. Participatory Action Research is an active collaboration of all stakeholders, leading to a blurring of roles defining 'researcher' and 'researched' and to an equal partnership between researchers and community stakeholders (Grant et al., 2008). It generally involves all partners collaborating in research that will then inform some sort of research-informed action (e.g., advocating for policy or systems change). The progression from the research to the action project is logical in PAR approaches, given that 'the path from knowledge generation to knowledge utilization is direct… since the same actors are involved in both activities' (Park, 1993: 3). PAR 'draws on the theoretical principles and ideas that relate to mutuality and understanding in the research process by those who are conventionally the focus of research' (Chataway, 1997: 457). Although the types of methods that can be used in PAR studies are diverse and embrace and adapt techniques from varied disciplines and practices (Aldridge, 2014), the voices of participants in all PAR are given highest priority, both in the design and objectives of the research. Within this methodological diversity, all PAR studies have a common objective to engage more effectively with participants and in ways that favour empathetic and democratic approaches to research (Walmsley & Johnson, 2003). In future studies, we will view participants with disabilities and their families as 'active participants, not only as subjects but also as initiators, doers, writers, and disseminators of research' (Walmsley & Johnson, 2003, p. 9).

Given the complexity of participatory approaches and the potential incompatibility between researcher/funder and community timelines and priorities, researchers often choose levels of participation that are the most convenient or easiest but that do not enable meaningful participation of key community stakeholders in all research phases (Aldridge, 2014), as was reflected in the first author's approach to her dissertation. More time is needed for PAR, as compared with traditional research, to allow for benefits of co-learning between community and campus partners and ultimately more relevant research programs and communication (Gray et al., 2010; Hoeft et al., 2014). Now, because of our initial partnership as a result of the dissertation work, we are better positioned to create true PAR relationships in the future, as characterized in the highest levels of the Turnbull et al. (1998) framework. In our future collaborative projects, we will use knowledge to improve existing services or support for people with disabilities, such as conducting research that could help individuals and families access medical care, have physical therapy, or gain specialized education services.

Conclusions

A partnership between researchers is a unique construction of different objectives and worldviews in which each individual brings his/her own strengths, experiences, and biases to the work. We would like to suggest that in order to overcome distrust, grounded in historical marginalization and continued questions of relevancy/use, partnership with local people with disability and researchers are essential for the foreign researcher. Partnering for disability research can be a complicated endeavour, fraught with ethical and political hurdles. Moving forward, North-South research collaboration should not be judged solely on the scientific results of that research, but also on how the collaboration was able to 'craft a sustainable, mutually beneficial working relationship that…must address inequity and put local priorities first, develop capacity with a long term perspective, and preserve the dignity of the local people by ensuring that the benefits of research will truly uplift their status' (Edejer, 1999: 440).

Researchers partnering for disability research need to understand that meaningful partnership takes time. The initial partnership described here is just a first step in what we anticipate will be a long-term collaboration. Researchers must build in the time to develop relationships and trust and to reflect upon the state of the partnership and make adjustments as required. We continually strive to enhance our partnership with one another and with other key stakeholders. In the described dissertation study, we did not achieve the highest level of partnership as outlined by Turnbull and colleagues (Turnbull et al., 1998), yet we aspire to higher levels of partnership in the future and will continue working toward our shared goal of improving the quality of life of people with disabilities and their families.

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