Postcolonial Encounters with Disability: Exploring Disability and Ways Forward Together with Persons with Disabilities in Western Zambia

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Rehabilitation Sciences Institute
University of Toronto

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Abstract

The economic and epistemological dominance of the global North has outlived colonialism. This postcolonial dynamic causes impairment in the global South and renders life more difficult for persons with disabilities (PWDs). This dynamic also limits the ability of people in the global South to respond to disability. This thesis aimed to challenge the postcolonial dynamic through the development of new ways to think about disability, and what to do about it, through a North-South collaboration with a North American rehabilitation provider and two disability groups and their members in Western Zambia.

This constructionist qualitative research project was informed by critical and participatory approaches to research. The participating groups included one based in an urban area and another in a rural area. A total of 81 individual members of the two groups participated. Data were generated through eight focus group discussions and 39 interviews and analyzed using thematic and reflexive analysis strategies.

The participants of this research were most concerned with poverty. The strategy that they suggested to improve their situation was help, a gift or grant of material resources shared in a
relationship of expected compassion. This research was complicated by power dynamics and differences between the participants and researcher with respect to priorities and ways of thinking. The complications likely impacted what people talked about and the way they talked about it. The complications also meant that this research was less collaborative than planned.

This research showed that PWDs in Western Zambia had concerns, and suggested strategies to improve their situation, that were different than those that are most common in Zambia. Since the current ways of thinking about disability in Zambia are largely informed by the concerns and priorities of the global North, this research points to possible alternatives that are based in the realities of the country.
Acknowledgments

“Wôch nan dlo pa konnen doulè wôch nan soley-la.” (Haitian proverb)

“The rock in the water knows not the pain of the rock in the sun.”

It might seem counter-intuitive that I have used a proverb from the Caribbean to acknowledge a thesis journey through southern Africa. Such is the value of the proverb: it is provocative, and insightful, precisely because its meaning is slightly mysterious. This thesis journey has been one of multiple perspectives and places; beginning before it started, and likely continuing after its completion. In the face of such multiplicity, it is literally impossible to explicitly acknowledge all who contributed. Here, I identify but a fragment of those worthy of mention. To the many others with whom I touched hearts, or in some cases connected so closely as to have our paths interline like the parallel strands of a double-helix, thank you. If I have been the person that I yearn to be, you will know that I am thinking of you fondly without the need for direct mention on these pages.

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Despite having spent a portion of my PhD time in southern Africa, this half-decade period has entailed more time close to family than any other in my adult life. To my Mom and to my Dad, thank you both for being endlessly encouraging as I continue my unconventional and difficult-to-describe career pathway. As time marches on, I am increasingly able to see the characteristics that we share, and the challenges and sacrifices that you have made in your lives, as I judiciously confront those in my life. To Bryan, I am endlessly impressed and enlivened by your ability to engineer *Cleaver brother time* against geographic and scheduling odds. I assure you that all that can be remembered will not be forgotten. To the many other family members with whom I have been able to spend more time these past few years, thank you for the wonderful moments of connection that we have been able to share.

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Chapter 1

1 Introduction

In this chapter I present the background that compelled me to pursue this thesis, a review of dominant trends in the framing of disability, the research objective and questions, and finally an overview of the organization of the thesis.

1.1 Background: Intervening in a postcolonial world

We live in a postcolonial world (Young, 2003). Although most of the colonial empires of European (and select non-European) imperial nations have been officially dismantled through the granting/winning of independences, important aspects of the colonial dynamic of metropole and periphery endure (Ashcroft, Griffins, & Tifflin, 2007). In this sense, the “post” in postcolonial is more indicative of colonialism’s ongoing legacy and re-creation, rather than indicating the era that followed the officially-recognized independence of colonies.

Postcolonialism is a way of looking at the postcolonial world (Young, 2003). In a very precise form, postcolonialism can be identified as the field of postcolonial studies, the premise of which is “to name and unpack the metropolitan genres of thought in which the global power of the metropole is embedded” (Connell, 2011, p. 1372). For my purposes, I am using postcolonialism as a principle and a perspective. Specifically, the principle is “the right of all people on this earth to the same material and cultural well-being” (Young, 2003, p. 2), despite the world being a systematically unequal place. The perspective is an active consideration of postcolonial dynamics into all aspects of my work.

Due to my commitments to another discipline, global health, I refer to the “binaristic hierarchy” (Ashcroft et al., 2007, p. 124) as global North/global South rather than metropole/periphery. Although global health has been critiqued for its disregard of postcolonialism (Crane, 2013), such that global health’s binaristic hierarchy might seem incongruent to that of postcolonialism, the terms North and South delineate the same geography and economic considerations as
metropole and periphery, even if they are used without the same historicity or political commitments.¹

Postcolonial dynamics are particularly relevant to this thesis in two realms: economics and knowledge. Economically, the current global distribution of wealth approximates the colonial arrangement, with the countries of the global North controlling disproportionate amounts of wealth as compared to their counterparts in the global South. The knock-on effects of this distribution are vast discrepancies between the standards of living, health, and opportunities available to people living in the global North as compared to those in the global South. With respect to knowledge, the metropolitan knowledge systems of the global North, premised upon Eurocentric (Ashcroft, et al., 2007) philosophical foundations have come to dominate the alternatives. This Northern (or colonizer) domination has occurred in concert with the subjugation of a variety of Southern (or indigenous) knowledge systems. In many ways, indigenous knowledges live on, albeit in alternative, hybrid, and subjugated forms. In other ways, indigenous systems have been crushed by the globally ubiquitous steamroller of (post)colonialism (Connell, 2011; Smith, 2012).

Although everyone is a participant in the ongoing postcolonial dynamic, I have played a more direct and active role than many. My most overt role in this postcolonial dynamic has been as a physiotherapist, traversing the boundary from my upbringing in the global North to intervene in the global South. I consider these traverses to be postcolonial encounters, experiences which are facilitated by postcolonial dynamics, and which lead to meetings of the different realities in the postcolonial world.² My personal point of entry into this equation is relevant, but only part of the story. Although I was aware of the world’s inequality, and I wanted to contribute to changing it,

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¹ The notion of a global hierarchy, typically a binary, circulates in many fields. Therefore, this notion of hierarchy has been identified according to multiple terms. These terms are also used with nuance that extends beyond the vernacular meanings of the words. These hierarchical terms are reviewed in Section 2.4.3, “The categorized world.”

² Postcolonial encounters include, but are not limited to, interpersonal encounters. I use the term to draw attention to multiple forms of encounters (e.g., between individuals, between groups, between peoples and places, between systems of knowledge). These encounters those that are facilitated by the structured dynamics of knowledge and economics that persist as legacies of colonization.
my encounters were enabled by the systematized realities of postcolonial knowledge and economics. First, it was taken for granted that my knowledge from the global North would be valuable in “other” parts of the world. This created a condition of possibility that made it logical to people in the North – and acceptable to peoples in the South – that I engage in this way. Meanwhile, my economic status as a Northerner made it logistically feasible for me to access these other places. Since this work was considered healthcare, this involvement also tied me into a community of like-minded people, through the field of global health. It was therefore a confluence of factors that led to my initial engagement: a budding postcolonialism conspired with postcolonial dynamics to facilitate my encounters with the other side of the world.

Through my engagement as a rehabilitation provider, the relationship between postcolonial encounters and postcolonialism became circular: in the process of living and working in the global South it became increasingly clear that the seemingly intractable challenges experienced in those places are related to postcolonial dynamics. To cite a high-level example, the global North-controlled World Bank and International Monetary Fund implemented series of Structural Adjustment Policies (SAPs) that reconfigured economies to fit neoliberal agendas and dismantle public services (Farmer, 2005). The results of such reconfigurations were visible at the community-level as fee-for-service former health facilities lay vacant and the communities faced the predictable problems of not having healthcare.

Although postcolonial dynamics can cause major problems for most people in the global South, there is reason to believe that the issues might be amplified for persons with disabilities. From my own postcolonial encounters, I would say that the lack of infrastructure and services for persons with disabilities limits opportunities. My initial understanding of these was economic: these limited opportunities were a result of the general state of poverty in the global South. Through the circular relationship between postcolonial encounters and postcolonialism, my understanding of this situation grew. One example of this growing knowledge base is Meekosha’s (2011) description of the way global North interests generate impairment in the global South through the sale of arms, dumping of pollution, and the creation of sweatshops. Troublingly, actors from the global North follow these impairment-generating activities with the
export of solutions to the problems of disability (including commercial ones), instead of looking for ways to stem the root causes (Meekosha, 2011).

Regardless of the extent to which postcolonial dynamics were responsible for generating impairment and disability, my involvement as a rehabilitation provider was squarely the result of the export of solutions (and the people to provide them) from global North to global South. According to this ethos, it was so certain that rehabilitation would improve the situation of persons with disabilities that it required no proof of its effectiveness beyond the delivery of services. Despite ample evidence of people with problems that I was trained to address, my personal experience as a rehabilitation provider contradicted the postcolonial knowledge regime’s confidence in my services. Instead, I found that the outcomes from my care were often poor, my efforts could not be applied comprehensively or to the roots of problems, there was constant doubt about the sustainability of my involvement, and I was possibly a sub-optimal use of limited resources.

In working as a physiotherapist in locations in the global South, I did experience some unquestionably positive outcomes to my interventions. In these cases, the clients with disabilities and I were able to develop common goals, my professional expertise contributed to the achievement of those goals, and the achievement was sustained over time, as determined by formal or informal follow-ups. These cases were rewarding, but they were exceptional. Far more common was the sentiment that my training, as a rehabilitation provider from Canada, did not fit the situations that I was facing in the global South.

I felt that the incongruence of training and needs was often premised on the notion of culture, in that it seemed that my understandings of disability, society, health, and healing were discordant with the understandings of the clients. Another common source of incongruence was realization that my own clinical services could address but a minute fraction of the needs that I was ostensibly striving to meet. Even after having considered the more dispersed approaches of capacity building through the training of additional professionals and raising funds for their subsequent employment, my contributions remained woefully inadequate in comparison to the needs, and dangerously dependent upon an ongoing engagement that I was not planning to
maintain. From the start of my engagement in the global South, it was clear that rehabilitation provided by practitioners from the global North was not an optimal strategy to improve the situation of persons with disabilities in the global South. Over the course of my engagement, I came increasingly to think that rehabilitation informed by practitioners from the global North might also be sub-optimal for many scenarios in many contexts.

As I have outlined above, the incentive for this thesis stems from the interplay of postcolonialism, as a principle and a perspective, and personal experience in the form of postcolonial encounters. Since my engagement has been focused on disability in a postcolonial world, it is here that I focus my attention. From this foundation of principle, perspective, and experience, I review the dominant ways of thinking about disability and what to do about it in the global South.

1.2 A review of disability in the global South

There are many persons with disabilities in the global South, and there are reasons to believe that their situation could and should be improved. The World Health Organization and the World Bank (2011) have conducted the most extensive exercise thus far to quantify disability globally, through the World Report on Disability. In crafting the report from a collection of survey data, the World Report on Disabilities identifies that the global South is the home of the majority of the more than one billion persons with disabilities alive on the planet (WHO & World Bank, 2011). More importantly, there is reason to believe that persons with disabilities face disproportionate limitations in opportunities as compared to persons without disabilities in their own countries or persons with disabilities in the global North. These discrepancies have created a compelling situation to understand and address.

In this section I review the efforts to understand and address the situation of persons with disabilities in the global South through three angles: the actors, the understandings, and the actions. Each of these angles provides a relatively brief snapshot of the postcolonial dynamic of disability. The angles articulate with one another in the sense that certain actors are more inclined to given understandings, which are often associated with given strategies. Despite the
articulation between angles, there is a benefit to looking at each one specifically since the connections between actors, understandings, and actions is not absolute. Moreover, in the instances where there are tight connections between actors, understandings, and strategies, there is variability with respect to the angle that is most fully described and critiqued.

Through the first of the three angles, I identify some of the most prominent categories of global actors engaging in disability in the global South. I then proceed to discuss some of the ways in which these actors understand disability, and then discuss the strategies that they use to address issues of disability.

1.2.1 Prominent global actors

Here I identify and describe a selection of prominent global, or globally-minded, actors who are involved with disability issues in the global South. The focus on global actors might give the impression that there are no local, national, or regional actors. This is not accurate: as Miles (1995) has previously detailed, many cultures have rich histories with respect to disability that predate colonial times. My focus on the global is not to discount the important roles played by individuals, organizations, and movements operating from different geo-political positionalities, it is instead to highlight those most closely connected to the postcolonial dynamic.

1.2.1.1 United Nations (UN) and specialized agencies

The UN is composed of its principal organs (e.g., the General Assembly, the Security Council) and its specialized agencies (e.g., UNICEF, UNDP, WHO). As the world’s preeminent intergovernmental structure, the UN is in a position of global influence, although this influence might be overshadowed by national or local concerns, or might not reach down to the grassroots level.

The UN has engaged in disability issues through its principal organs and through its specialized agencies. Examples of engagement from the General Assembly include the World Programme of Action Concerning Disabled Persons (United Nations, 1982), the International Decade of Disabled Persons, 1983-1992 (United Nations, 2004), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1994), and most recently, the
Convention on the Rights of Persons with Disabilities (United Nations, 2006). I discuss the Convention in greater detail below, in Section 1.2.3.3.

There is no single UN specialized agency created to focus on disability. Instead, disability is an issue that is addressed by numerous specialized agencies, but among these it has been the World Health Organization (WHO) that has been the most prominent. The WHO has developed specific components with disability mandates, such as the Violence and Injury Prevention and Disability cluster, and the Disability and Rehabilitation (DAR) team. Through the leadership of these components, the WHO has initiated its own programs and activities to address disability, including those that have set standards that other agencies have followed. The WHO has also been a leader among the specialized agencies in terms of attracting partners to specific initiatives.

Of the specific WHO initiatives, I discuss two separately, due to their international prominence and impact. The first of these initiatives is the International Classification of Functioning, Disability, and Health (WHO, 2001), which I address in Section 1.2.2.4. This classification system, most commonly referred to by its acronym ICF, was developed by the WHO but has had broad effects through the UN system. The second of these initiatives is community-based rehabilitation (Khasnabis & Motsch, 2010), or CBR, which I address in Section 1.2.3.2. The WHO originally developed CBR independently, but has attracted other specialized agency partners through subsequent iterations of CBR.

One additional WHO initiative, the “WHO Disability Action Plan 2014-2021” (World Health Organization, 2015), merits mention due to its disability focus, despite not having the prominence or history of the ICF or CBR. This action plan focuses on three objectives: health services, rehabilitation, and data collection and analysis. The health services objective is oriented towards reducing barriers, and the data collection and analysis objective relates primarily to the disaggregation of data to allow comparisons between persons with and without disabilities. Therefore, these two objectives are essentially disability considerations applied to activities intended for the broader population. Of the three objectives, it is only rehabilitation that is focused on disability and persons with disabilities. Among the strategies that I discuss in this
review, I include rehabilitation (Section 1.2.3.1). I will refer to aspects of the WHO Disability Action Plan in that section.

1.2.1.2 International non-governmental organizations (INGOs)

International non-governmental organizations (INGOs) are a subset of the larger category of non-governmental organizations (NGOs). I first discuss the larger category of NGOs in order to bring greater clarity to the subset of INGOs.

Non-governmental organizations are defined by what they are not. By grouping any organization that is non-governmental into a single category, we create a category that is inherently diverse and heterogeneous. Willetts (2012) attempts to bring precision to this heterogeneity by discussing the relationship of NGOs to social movements, pressure groups, and interest groups, ultimately concluding that it is impossible to make absolute distinctions between these categories. Nonetheless, the term NGO is typically applied to an organization focused upon social goals, and (at least nominally) distinct from the overtly political and commercial goals of political parties and profit-oriented businesses. For the purposes of this thesis, I am interested in NGOs as not-for-profit, non-state actors. This definition remains broad, but sets identifiable boundaries to a category that otherwise has the potential to be limitless.

In addition, due to my foundation in postcolonialism, I am interested in NGOs that have global scope. These are typically identified as a subset of NGOs that are international in their nature. International non-governmental organizations,

are [typically] based in the various countries that belong to the OECD (Organisation for Economic Cooperation and Development), in which the donor countries are united…They get framework funding, for instance, or serve as subcontractors for development programmes and humanitarian aid in the global south. At the same time, they finance some of their international activities with fund-raising campaigns and philanthropy. (Tujan, 2015)

As Tujan Jr. (2015) discusses, INGOs are key players in a postcolonial geo-political dynamic that is tilted in favour of the interests and influence of the global North. Regardless of this
potentially problematic position, INGOs are engaging in disability issues in the global South in influential ways.

Among INGOs, there is a small number focused on disability issues, and a larger contingent that might consider disability among their activities even if it is not the focus. Among INGOs, those focused on disability issues are most clearly identified through membership with the International Disability and Development Consortium (IDDC, 2016). Those INGOs that consider, but are not focused on, disability create a category that is larger and more nebulous, but includes Oxfam, CARE, Plan, World Vision, the International Committee of the Red Cross, and Médecins sans frontières to name but a few.

1.2.1.3 Professions and professionals

Another set of prominent global actors are the professions and professionals involved in addressing disability. I am considering a profession to be “a paid occupation, especially one that involves prolonged training and a formal qualification” (Oxford dictionaries, n.d.). As prominent actors engaged in disability in the global South, profession/als are often involved through the previously-mentioned categories of the UN and INGOs, but are also engaged in more independent ways.

My consideration of professions, as it relates to the postcolonial dynamic of disability, is most clearly informed by my own participation as a rehabilitation professional. This participation allows greater perspective with respect to the rehabilitation professions, which are typically understood to be healthcare providers with particular interest and engagement with disability issues. Rehabilitation professions are not alone in their focus on disability; the International Association of Special Education and the World Association of Sign Language Interpreters are examples of others, yet the rehabilitation professions stand out for their prominence.

The rehabilitation professions typically have their origins in the global North, with gradual expansion into the global South. This trend is evidenced through the history of physical medicine/physiatry (ISPRM, n.d.), the nationalities of the executive board of the International Society for Prosthetics and Orthotics (ISPO, n.d.), and the historical membership composition of
the World Confederation of Physical Therapists (WCPT, 2016) and World Federation of Occupational Therapists (WFOT, 2012).

In effect, professions are complex bodies that function in collective and individual ways. As outlined in the previous paragraph, each of the rehabilitation professions has an international federation of national associations. These associations are led by members of the profession, but also lead the profession in their own country, and to a certain extent, internationally. These associations also interface with regulatory, educational, and governmental structures. In addition, individual professions often have a degree of power and privilege as individuals with increased educational, social, and economic capital than many other citizens in their societies.

1.2.1.4 Disability movement

By the disability movement, I am referring to the actors involved with advocacy for persons with disabilities. These actors are primarily, but not exclusively, persons with disabilities themselves. The disability movement is responsible for the social model, which I discuss as an understanding of disability in Section 1.2.2.3. The movement is also actively engaged with the strategy of the Convention for the rights of persons with disabilities (UN, 2006), which I discuss in Section 1.2.3.3. In the current section, I focus on the history and trajectory of organizations in the disability movement. By focusing on organizations, I am able to follow documented histories that demonstrate a trajectory of increasing leadership among persons with disabilities themselves, of a migration of engagement from global North to global South, and of the influence of advocacy on scholarship.

Groups of persons with disabilities have created a formidable movement through organizations such as Disabled Peoples’ International (DPI). With 130 national members (DPI, n.d.), including many in the global South, DPI has now extensive global reach. Disabled Peoples’ International was not always global in its nature, however, especially since its history and influences predate the founding of the organization in 1981. Disabled Peoples’ International was founded as the response to frustration of professional dominance in Rehabilitation International (Asia-Pacific Development Center on Disability, n.d.), a much older organization “comprised of people with
disabilities, service providers, government agencies, academics, researchers and advocates working to improve the quality of life of people with disabilities” (RI Global, n.d.). Rehabilitation International has its roots in the American Midwest before expanding into more than 100 countries (RI Global, n.d.). Thus, in effect RI, and the breakaway DPI, have both followed the colonizing trajectory that begins in the global North and expands Southward.

The history, development, and reach of Rehabilitation International and DPI represent a pan-disability or cross-disability approach to the organizing of persons with disabilities. In addition to this, there are examples of parallel global federations for narrower slices of the disability movement through the World Blind Union (WBU, n.d.) and the World Federation of the Deaf (WFD, n.d.), as examples. Both of these organizations follow a similar growth trajectory: beginning with national members in the global North and expanding to include the global South.

1.2.2 Dominant understandings of disability

Those who engage with disability have their understandings of what disability is, regardless of whether that conceptualization is conscious or unconscious. Who are the disabled? How does one determine if a person is disabled or not? Is it even important to make such determinations? What does disability mean for a person, for a family, for a community? The task of identifying the essence and the boundaries of disability can be challenging in any setting, but is further complicated by a postcolonial dynamic involving multiple contexts and cultures. Here I review some of the dominant understandings of disability that have informed postcolonial engagement.

I describe and critique five dominant ways of understanding disability. I am referring to these as understandings as dominant, in the sense that there is a hegemonic notion (Ashcroft, et al., 2007) that these understandings from the global North are superior to local understandings. Accordingly, these understandings have been able to crowd out alternatives in the larger postcolonial world. I have referred to each of these understandings of disability as either a model or a framework, depending upon common usage. In some cases, the understandings were explicitly developed and intended to operate as a model or framework. In the remaining cases, the given understanding of disability evolved according to other concerns. In these cases, where
the understanding of disability evolved more implicitly, the ways of understanding were identified as models as part of a critique. Four of the understandings that I discuss are presented with a sense of chronological order, namely the charity, medical, and social models, and the ICF framework. These are presented chronologically because each subsequent understanding emerged with some awareness of the understanding(s) that preceded it. Unlike the first four, the fifth understanding, the “traditional model,” evolved in its identifiable singularity because of the postcolonial dynamic. For this reason, I present it last.

1.2.2.1 The charitable model

As understood through the charitable model, persons with disabilities are seen to be unable to generate or claim adequate resources themselves, and therefore require charitable support. Although disability is understood to be tragedy through this model (Oliver, 1990), understanding disability through this model can lead to charity, which can mean resources to be allocated to improve the situation of persons with disabilities. Nonetheless, this understanding of disability leads to the loss of individual agency for persons with disabilities, which, for many, renders the model unacceptable.

The critique regarding the loss of individual agency has been particularly damaging to the charitable model in the global North, where individual independence and agency are generally understood to be important qualities. Despite this, the charitable model has been exported from the global North to the global South, particularly through the work of missionaries in the colonial era (Grech 2015).

1.2.2.2 The medical model

As opposed to the charitable model, where persons with disabilities are not understood to be independent contributors to society, the medical model posits that the disabilities of individuals can be remedied (Oliver, 1990). According to this model, disability is a deformity or deviation of a person’s body or mind that impedes that person’s capacity to function. By addressing the deformity or deviation, particularly through forms of medical care, the disability can be reversed, lessened, or mitigated to allow a higher level of function.
The medical model has led to the development of specialized services, particularly rehabilitation, to reverse, lessen, and mitigate deformities or deviations. I discuss rehabilitation in more detail in Section 1.2.3.1. The specialized services created by a medical model understanding of disability have allowed important advancements, but have also come with important downsides. The notion that disability can be fixed is founded upon, and reinforces, a notion that disability is a problem. As stated by Brisenden (1986), the medical model:

has led to a situation where doctors and others are trapped in their responses by a definition of their own making. They cannot respond in ways that go outside the parameters of a view of disabled people which they themselves have created (p. 176).

The medical model developed in the global North, in tandem with a growing medicalization of society. It was first transported to the global South during the colonial era “as Western medical professionals imported…the European specialised institution” (Grech, 2015). In subsequent years, the growing prominence of the medical model, through its tight link with rehabilitation, is apparent through the growth of the rehabilitation professions in the global South (as described in Section 1.2.1.3).

### 1.2.2.3 The social model of disability

Unlike the charitable and medical models, each of which developed implicitly, the social model of disability was an understanding that was explicitly articulated as a model. Indeed, the social model was developed as an intentional contrast to previous understandings. While charitable and medical models located disability in the bodies and minds of individuals (Oliver, 1990), the social model was articulated as an attempt to change the focus to society. As stated in the first articulation of the social model: “In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (Union of the Physically Impaired Against Segregation, 1976, pp 3-4).

The social model was novel in its differentiation of impairment from disability. The essence of this differentiation was to identify and distinguish the individual from the societal aspects of disability. Whereas impairments were features of individuals that might be inherently
problematic, or might simply be reflective of human diversity, disability (and its associated problems) were features of a non-inclusive society.

The social model grew from the disability advocacy of the Union of the Physically Impaired Against Segregation (UPIAS), a disability self-advocacy organization in the United Kingdom. The model was further developed by Mike Oliver, a prominent early contributor to the field of disability studies (Albrecht, Ravaud, & Stiker, 2001). From this foundation, the social model has been exported globally. The diffusion of the social model is a process that has provided significant benefits to the disability movement for its ability to reframe the way that disability is viewed, particularly in places where the charity and medical models were dominant. This diffusion is not without its limitations, however, and might be less appropriate for peoples and places facing markedly different circumstances than those that stimulated the social model’s creation. As stated by Grech (2009) “this social model is problematical across cultures, since it remains the product of a specific space and time, articulating the concerns of white, middle class, educated, western, disabled academics” (p. 772).

1.2.2.4 The ICF framework

The International Classification of Functioning, Disability, and Health, more commonly referred to by its abbreviation *ICF*, was established by the WHO as part of its classification regime (WHO, 2001). Beyond its role as a classification tool, the WHO also presents the ICF as a framework (World Health Organization, 2002), encompassing a definition of disability, based upon a collection of constituent constructs that are held together through a model (see Figure 1.1). According to the ICF, disability is “an umbrella term for impairments, activity limitations and participation restrictions” (WHO, 2002, p. 2).
Each of the constituent constructs of the ICF is defined and described in greater detail. These definitions and descriptions enable a structure that also allows each of these constructs to be classified according to the ICF system (ICF Browser, n.d.). The fundamental aspect of the ICF that is most relevant to this discussion is the ICF’s attempt to incorporate both the medical and social models by framing the ICF as a biopsychosocial model (WHO, 2002, p. 9). On this basis, the ICF has grown out of two models that were developed in the global North: the medical model as part of the global North’s increasing medicalization, and the social model as a particular response to the medical model by persons with disabilities.

1.2.2.5 The “traditional model”

The “traditional model of disability” is distinct from the previous four understandings of disability that I have presented inasmuch as this model has been identified at a higher level of
abstraction. What I refer to as the traditional model, Ingstad (1999) refers to as “the myth of
disability in developing nations” (p. 757). The premise behind the traditional model is that in all
“traditional cultures” (of the global South), disability is understood to be a spiritual phenomenon
with catastrophic consequences for persons with disabilities.

It is important that I distinguish what I am calling the traditional model from other cosmological
understandings of disability. For example, Roush and Sharby (2011) describe a “moral model”
with “positive and negative perceptions of disabilities” (p. 1716), even if the negative
perceptions might be more prevalent. Important in Roush and Sharby’s (2011) characterization is
a sense of nuance, with respect to the ways in which spiritual understandings might be similar or
could be different according to different societies or belief systems. Although Roush & Sharby
(2011) are creating a category of understandings through their description of a moral model, it is
a category with diversity.

By contrast, what I refer to as the traditional model is premised on a sense of homogeneity.
According to the traditional model, if there is a diversity of understandings of disability in
traditional cultures, this diversity is irrelevant. As Ingstad (1999) argues, it is recognized that
there are cases of spiritual beliefs leading to mistreatment of persons with disabilities in the
global North, yet “we do not use these [cases] to create a general picture of behavior in Europe
or the USA” (p. 757). By contrast, from the global South, “come stories about hiding, neglect,
and even murder of infants with an obvious impairment….as a general and current
problem…seen as ‘attitudes’ resulting from ‘beliefs’” (p. 757).

From my experience in multiple locations in the global South, the traditional model is regularly
cited as a problematic belief system by actors operating with an understanding of disability that
is congruent to any of the four understandings that I have described above. Even in recent
documents intended for global audiences, “traditional beliefs” are framed as a generalized entity
that is antithetical to progress (WHO, UNESCO, ILO, & IDDC, 2010, p. 15). The recognition of
alternative belief systems among actors is likely a positive, but approaching this recognition
through what I am calling the traditional model is problematic for two reasons. First, viewing
cultural perspectives of disability (or things similar to it) through the lens of the traditional model
allows the viewer to homogenize a variety of perspectives into a single category that is “traditional.” A second problem with the traditional model is that it creates a foundation for actors to believe that there is “no worthwhile cultural heritage or traditional practice on which anything ‘modern’ might be built” (Miles, 2007, p. 3).

The traditional model is distinct from the charitable, medical, social, and ICF in that it is not practiced by any actor approaching disability as part of the postcolonial dynamic, but instead constructed as a homogenous pre-existing understanding by those same actors. Importantly, the creation of the traditional model, as a homogenous and oppressive package of “pre-modern” beliefs, has provided postcolonial actors justification to intervene according to imported understandings of disability without further consideration of local understandings. In this sense, the traditional model has been a powerful understanding; one that has contributed to the dominance of the first four understandings that I described above.

1.2.3 Dominant strategies to improve the situation of persons with disabilities

As previously stated, there is reason to believe that persons with disabilities in the global South face disproportionate limitations in opportunities as compared to persons without disabilities in their own countries or persons with disabilities in the global North. Because of this situation, many of the prominent actors described above have developed strategies to improve the situation of persons with disabilities in the global South. I have identified a selection of strategies as dominant. These dominant strategies are those supported by hegemony (Ashcroft, et al., 2007) and therefore have widespread support through global structures linked to the postcolonial dynamic. Dominant strategies can often be linked to a given understanding of disability, although in some cases (e.g., community-based rehabilitation) the nature of the strategy and the understanding of disability to which it is linked can evolve. Some of the strategies have influenced the development of other strategies. In order to reflect these influences, I present the strategies with a sense of chronology. This chronologically-minded order allows me to describe the ways in which rehabilitation influenced community-based rehabilitation, and disability advocacy influenced the Convention on the rights of persons with disabilities. For each of the
strategies, I identify the actors who are most invested in them, the understandings with which they articulate, in order to make connections between these strategies and Sections 1.2.1 and 1.2.2.

1.2.3.1 Rehabilitation

Rehabilitation has been defined as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (WHO & World Bank, 2011, p. 96). This definition is disability-focused; whereas it is also possible to consider rehabilitation as a conglomerate collection of tasks, as did Banja (1996) by listing burn, cancer, psychiatric, sports, vocational, pain, cognitive, and behavioural rehabilitations (p. 282). It is also possible to identify rehabilitation through the rehabilitation professions (i.e., physiatry, prosthetics, occupational therapy, physiotherapy), specific institutions such as the Toronto Rehabilitation Institute, or a scientific field (Stucki & Grimby, 2007). Rehabilitation is generally considered to be a health or medical service, and is sometimes differentiated from community-based rehabilitation through the label institution-based rehabilitation (Helander, Mendis, Nelson, & Goerdt, 1989, p. 16).

Rehabilitation is typically understood to be a health service and is quite closely connected to the medical model of disability (see Section 1.2.2.2). Accordingly, as the UN specialized agency responsible for health and health care, the WHO (2015) has identified rehabilitation as one of three objectives in the “WHO Disability Action Plan 2014-2021.” Within the action plan, there are seven actions related to rehabilitation, calling on member states to: (1) provide leadership for policy development, (2) provide adequate resources, (3) build a sustainable professional workforce, (4) expand, strengthen, and integrate services across the continuum, (5) make available assistive technologies, (6) promote access to a range of services, and (7) engage persons with disabilities and their families (WHO, 2015).

It is possible to see the WHO’s interest in rehabilitation as misplaced, and likewise question the prominence of the WHO in the UN’s response to disability. As I described in Section 1.2.2.2, rehabilitation has very close links to the medical model. These links to the medical model have
led to important critiques about the way the rehabilitation is conceived (Whalley Hammell, 2006). Moreover, rehabilitation has migrated from global North to global South according to the expansion of the medical model and the growth of the rehabilitation professions (see Section 1.2.1.3). This migration is reason to question the alignment of rehabilitation to realities in the global South.

Despite these valid critiques, there are reasons to support the continued growth and expansion of rehabilitation. According to the WHO and the World Bank (2011) “for some people with disabilities, rehabilitation is essential to being able to participate in education, the labour market, and civic life” (p. 94). Through my experience as a rehabilitation provider in the global South, I was often skeptical of the value of rehabilitation, yet I also witnessed situations where rehabilitation led to important positive outcomes, and others where inadequate rehabilitation led to catastrophic negative outcomes.

The promise of rehabilitation in the global South juxtaposed with the critiques has created further questions. Some of these questions relate to resources, for example, how can rehabilitation be conceived in a way affordable to the many low-income countries of the global South? A related question is whether rehabilitation provides sufficient value for the resources involved, given its typical implementation with well-educated professionals, as compared to alternative options? Some of the questions about rehabilitation relate to “culture,” asking whether a rehabilitation philosophy developed in one cultural context is appropriate in another (e.g., Iwama, Thomson, & Macdonald, 2009).

1.2.3.2 Community-based rehabilitation (CBR)

Community-based rehabilitation originated in the 1970s part of a WHO initiative to address the challenges of rehabilitation provision in the global South (Helander, 1993). The development of CBR was justified on the basis that there were insufficient resources and rehabilitation professionals in the global South, such that it could not be rolled out the way that it had been in the global North (Helander, 1993). In its early years, CBR was described as “situations where resources for rehabilitation are available in the community [because of] a large-scale transfer of
knowledge about disabilities and of skills in rehabilitation to the people with disabilities, their families, and members of the community” (Helander, et al., 1989, p. 16). In essence, CBR was originally conceived as a mechanism to implement medical rehabilitation in the global South, but with greater speed and less cost due to a greater reliance on information transfer and volunteers as opposed to trained professionals.

In the 1990s, the WHO partnered with other UN specialized agencies to create a joint position statement on CBR (ILO, UNESCO, & WHO, 1994). As the organizational leadership behind CBR became more varied, the strategy moved beyond its history of health care and medical rehabilitation. By 2003, stakeholders involved with CBR had noted “the evolution of CBR from a model that was often viewed as medical to one that promotes the rights of people with disabilities.” Shortly thereafter, CBR was redefined as “a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities” (ILO, UNESCO, & WHO, 2004, p. 2).

The agencies responsible for CBR have further refined the strategy through the development of guidelines (Khasnabis & Motsch, 2010) and the presentation of a model of activities that could be considered as part of a CBR program, referred to as the CBR matrix (see Figure 1.2). The CBR matrix is presented in terms of five components: health, education, livelihood, social, and empowerment. Four of the included components were selected on the basis of the relation to key community development sectors, while “the final component relates to the empowerment of people with disabilities, their families and communities” (WHO, et al., 2010, p. 24). Each of the five components is further subdivided into five elements, such that there is a total of 25 elements. The guidelines clearly state that “programmes are not expected to implement every component and element of the CBR matrix” (WHO, et al., 2010, p. 24), but instead select those that are relevant to their specific situation. The guidelines encourage those developing programs to partner with sectors to address important needs not covered by the programs’ specific activities.
Community-based rehabilitation has likely brought services to many persons with disabilities who would not otherwise have access. Despite this important benefit, it has also been critiqued as a buzzword that actors use to rebrand old ideas as innovative (Miles, 2007). Moreover, a recent scoping study of literature on CBR in the global South demonstrated that the majority of the first authors were affiliated with institutions in the global North (Cleaver & Nixon, 2014). This distribution of authorship creates questions about who is generating the knowledge of CBR and whether this arrangement is appropriate.

1.2.3.3 Convention for the rights of persons with disabilities (CRPD)

The CRPD (UN, 2006) is a human rights treaty designed to make “existing [human] rights inclusive of, and accessible to, persons with disabilities” (WHO, et al., 2010, p. 22). The CRPD is a central document that reflects the United Nations’ highest consideration of disability, following the foundations created by the World Programme of Action (UN, 1982), the International Decade (UN, 2004), and the Standard Rules (UN, 1994).
The CRPD is a document of 50 articles “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UN, 2006, Art. 1). The importance of equality is further emphasized through the premise that rights should be realized without “discrimination on the basis of disability” (UN, 2006, Art. 2). The CRPD has been widely adopted on a global basis; at this time there are currently 160 signatories (United Nations, n.d.). The global disability movement was influential in seeing the CRPD implemented and has used the CRPD as a rallying point for further action. The CRPD has also had a cross-influence on other activities within the UN family, as evidenced by its reference in the CBR Guidelines (Khasnabis & Motsch, 2010) and the WHO Disability Action Plan (WHO, 2015).

As an instrument of the United Nations, the CRPD is designed to have global relevance. Although human rights treaties have been powerful tools for many spheres of human well-being, Meekosha and Soldatic (2011) demonstrate that the CRPD is premised in the global North-derived values of individualism and a detachment of interest in the causes of impairment in order to focus on discrimination. Because of these premises, Meekosha and Soldatic (2011) argue that the CRPD specifically, and human rights disability discourses in general, are incongruent to the lived experience of persons with disabilities in the global South.

1.2.4 Summary of the review of disability in the global South

The actors engaged in the postcolonial dynamic of disability and the dominant understandings of disability and strategies to improve the situation of persons with disabilities are diverse and commonly have the interest of people with disabilities as a driving motivation. However, they share another commonality: all have their roots in the global North. This does not mean that they are without merit or inherently harmful, but it does mean that their dominance in global South settings should be questioned.

1.2.5 Statement of the research problem

Through an interconnected process of personal experience and a review of academic literature, it has become apparent to me that the current ways of thinking about disability, and what to do
about it, in the global South are limited. The landscape of ways of thinking is dominated by ideas that were generated in the global North. Because of insufficient awareness of the situation in the global South, and the infusion of ideas pushed uncritically into the void from actors and organizations in the global North (Miles, 2007), there is an urgent need to develop new ways of thinking that are contextually-grounded to situations in the global South. These new ways of thinking must be developed with acknowledgement of the contexts in which they were generated. Furthermore, it is necessary to interrogate the enduring influence of postcolonial dynamics as part of the research process.

1.3 Research purpose and objectives

1.3.1 Purpose:
To co-construct new ways of thinking about disability, and what to do about it, in the context of a postcolonial encounter, involving a North American-trained rehabilitation professional and disability groups and their members in Western Zambia.

1.3.2 Objectives

1. To describe the unique context and nature of one urban and one rural disability group in Western Zambia, and explore these groups’ expressed concerns.

2. To explore how strategies to improve the situation of persons with disabilities are framed within the accounts of participating disability groups in Western Zambia.

3. To critically reflect on the experience of conducting this thesis research through the lenses of (a) a critical social science perspective (CSSP), and (b) global health research ethics, in order to better understand the research process.

1.4 Thesis organization

I have prepared this thesis in manuscript style. I opted to use manuscript style in order to prioritize and expedite the dissemination of academic knowledge created by thesis research. The thesis consists of eight chapters. The chapters are further subdivided into multiple levels of
sections. In Chapters 1, 2, 3 and 8, I present overarching material relevant to the entire thesis. I provide an overview of each of these chapters below. In Chapters 4 through 7 I present focused literature reviews, methods, results, and preliminary conclusions through a series of manuscripts. I composed each one of these chapters as an independent manuscript for submission for publication in a peer-reviewed journal. The manuscripts are complementary to each other and collectively address the overall purpose of the study. I present an overview of the chapters of this manuscript style thesis in Table 1.1.

In Chapters 1, 2, and 3, I present the foundations of the thesis. In the preceding sections of Chapter 1, I presented the problem that the thesis aims to address and the guiding purpose and objectives. In Chapter 2, I present the grounding of the thesis: the approach I took to this research, an assessment of my positionality, a review of the context of Zambia and Western Province, and key concepts. I present the methodology and methods of the thesis in Chapter 3.

In Chapter 4, I present a manuscript that addresses the first specific objective of the study, “to describe the unique context and nature of one urban and one rural disability group in Western Zambia, and explore these groups’ expressed concerns.”

In Chapter 5, I present a manuscript that addresses the second specific objective, “to explore how strategies to improve the situation of persons with disabilities are framed within the accounts of participating disability groups in Western Zambia.”

In Chapters 6 and 7, I pursue the third objective “to critically reflect on the experience of conducting this thesis research…in order to better understand the research process.” In Chapter 6 I use the experience of “disjunctures” (Mandel, 2003) between my expectations and my lived experience as a researcher as a point of departure for a reflexive analysis. The reflexive analysis is guided by a critical social science perspective as described by Eakin, Robertson, Poland, Coburn, & Edwards (1996). Through this reflexive analysis, I identify productivity as a hidden assumption that I brought into this thesis research project. I then trace the prior experiences and interpersonal, institutional and societal influences that could have informed the interest in productivity, propose two alternative ways to understand productivity, and explore the
ramifications of these influences on disability research in the global South. In Chapter 7, I review the thesis research through the lens of global health research principles (CCGHR, 2015) in order to make sense of a discrepancy between the aspirations that I had created for the project and the actual outcomes.

I use Chapter 8 to draw together the thesis: addressing the study objectives by summarizing the manuscripts, identifying the key contribution, and articulating the implications of this research for policy and practice, theory, and future research.

This thesis presents alternative perspectives of disability and North-South collaboration that are grounded to postcolonial realities in the global South through the empirical and reflexive contributions of the four manuscripts. Accordingly, this work can challenge the domination of worldviews and strategies from the global North that are being exported uncritically to the global South.

Due to the manuscript style format of this thesis, there is some repetition and redundancy between manuscript chapters. Furthermore, Chapters 1, 2, 3, and 8 have been drafted for the specific purpose of making the whole thesis more cohesive and coherent. Some aspects of presentation vary between the chapters that are submitted as manuscripts since each was developed for a particular audience and journal. This variation includes the voice of the writer (impersonal vs. first person singular vs. first person plural) and the citation formatting. I generally refer to this collective work as a thesis, but in some chapters have instead named it a dissertation.
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1.5 References


Chapter 2

2  Grounding: positionality, approach, context, and concepts

In this chapter I present fundamental grounding elements that I used to inform the research process. These grounding elements build upon the foundations of postcolonialism, postcolonial encounters, and my critique of the dominant framings of disability that I presented in Chapter 1. The grounding elements that I present in this chapter include my positionality, the overall approach that I took to this research, a thorough description of the research context, and a description of key concepts.

2.1  Positionality

In reflecting upon her own fieldwork in Bangladesh, Sultana (2007) compels us to “[be] reflexive about one’s own positionality [and] how one is inserted in grids of power relations and how that influences methods, interpretations, and knowledge production” (p 376). Reflexive analysis of positionality often begins with a list of identifiable characteristics as a framework to assess their potential impacts (Cousin, 2010). I support this as a starting point, since these characteristics are important in the grids of power relations, but see this as insufficient. I think that it is also necessary to unpack the additional characteristics and life experiences which will influence how a researcher thinks about her/his work and how the social interaction of research engagement unfolds (Berger, 2015; Bradbury-Jones, 2007).

2.1.1  Apparent characteristics

I identify as a heterosexual cisgender male and am currently in my mid-30s. Racially, I have always been identified as White. I do not consider myself to be disabled, and with the possible exception of temporary impairments caused by illness or injury, I cannot remember anyone having referred to me as having a disability. I grew up in suburban Canada speaking English as my first language. Both of my parents were usually employed, and I would consider my upbringing socially and materially comfortable even though my parents separated when I was a teenager. I completed two university degrees prior to beginning my PhD, a bachelor’s degree in
physiotherapy and a master’s degree in epidemiology. I completed these degrees without student
debt, primarily because of awards and bursaries that I secured without onerous application
procedures. As an adult, I have never experienced a period of involuntary unemployment lasting
more than a few weeks.

I imagine that when others see me or meet me for the first time, it is the pieces of information
described above that they are easily able to absorb, and therefore use to relate to their own
situation. In addition to these, I believe that there are aspects of my upbringing, professional
experiences, and ethno-cultural and linguistic factors that influence my choices as a researcher.
All of these elements combine to influence my positionality in the research field.

2.1.2 Individualistic upbringing

Through my upbringing in suburban southern Ontario in the 1980s and 1990s, I was surrounded
by certain values and ways of life. By this, I do not imply that these values and ways of life were
universal – in expression and practice I can easily cite exceptions – but these were common,
respective, and for me, formative. The strongest values and ways of life related to individualism
and consumptivism. In my upbringing, and in the larger community that surrounded it, it was
expected that each person could, and would, take care of him/herself through responsibility and
labour. Unless otherwise qualified, “success” meant wealth. Family was important, but not close.
There were expectations to be active and to achieve, opportunities which were apparently
available to most in the community. For those of us who had those opportunities, we did not
spend much time talking about those for whom they were not available, likely because we were
busy being active and trying to achieve. The dominant built form of my community was spatial
separation, with planned and enforced separation between residential, commercial, recreational,
and industrial uses. In this environment, “regular people” owned well-maintained detached
houses for family life, and traveled, almost exclusively by private automobile, for most other
aspects of life. While growing up, I never saw a reason to think about these patterns as anything
but natural, let alone see them as problematic.
Much of my adult life has been focused on using selected aspects of my upbringing as resources to challenge the rest of it. With time, I began to see the characteristics of my upbringing as products of historical and geo-political phenomena, and not merely as the inevitable progress of hard work. I started to see individualism and consumptivism as related, and strived to orient my professional and social energies to counter these.

My process of resistance was initiated through my early postcolonial encounters. These started with the question “How can I help others access the resources that I have been able to access?” With time, that question evolved to “How can I help change the power dynamic that allows the global North to take more than it needs?” Regardless, my concerns were grounded in the notion that there was something fundamentally unfair about the global distribution of resources, and the power relations that sustains this distribution. Becoming aware of this unfair global distribution caused me to engage in activities to counter this phenomenon and pursue social justice. The urgency to act was further stimulated by a growing recognition of limited natural resources and anthropogenic environmental degradation; two situations largely caused by unsustainable consumption. Ultimately, the considerations led me to focus more on “non-material,” socially-grounded, aspects of life, with a conscious attempt to re-orient my economic engagement away from consumptivism (e.g., Latouche, 2009). Accordingly, these considerations led me to reject the neoliberal penchant for an economy based primarily on rationally-minded impersonal transactions (Berghs, 2014) and even become skeptical about the merits of capitalism more broadly.

These perspectives influence the questions that I ask and the ways that I ask them. In turn, these all affect the type of researcher that I am and the choices I make. In a parallel sense, these perspectives have also influenced my professional activities, which has further shaped my worldview.

2.1.3 My (specific) postcolonial encounters

Although I have visited locations in the global South as a tourist, my formative experiences were in professional roles. These roles included volunteer, in-kind compensation, and paid experiences
in Malawi, Haiti, Mushkegowuk Cree territory\(^3\), South Africa, and Cameroon. In each of these experiences, I was considered to be a physiotherapist\(^4\), and engaged in some aspect of health and/or disability work. Through these experiences, my roles included clinical practice, service development and coordination, professional and public education, research, policy development, and disability advocacy. In each of these experiences, I strived to learn about the history and culture of the place, and found this very influential to my involvement. This appreciation for the particular informed my contributions and was also a source of energy and personal interest. These encounters have instilled in me a desire to come to know a limited number of places and peoples in greater depth, rather than spreading my involvement more widely.

2.1.4 Ethno-cultural heritage and linguistic interest

I have always described my ethno-cultural background as “half French-Canadian, half English-Canadian.” Despite having grown up in an area where English was nearly exclusive as a public language and being a unilingual English-speaker for most of my youth, my French-Canadian identity was a source of pride and distinction. Ultimately, I struggled to improve my proficiency in French to attain fluency and immersed myself in French-Canadian culture as a young adult. Through this process I learned that I could, at-best, achieve the status of passable outsider when in majority French language environments, a feat that was simultaneously rewarding and disappointing. Over the same period, I discovered that my mother’s Franco-Albertan family had nearly completed its Anglicization and assimilation into the dominant culture. For me, becoming French while staying English became an even more important part of my personal identity, within my family and beyond. More than any other aspect of identity, learning language and

\[^3\] By most accounts, this territory on the shores of James Bay is within Ontario, and therefore part of Canada. In discussing “the categorized world” (see Section 2.4.3) I describe why this territory and its people are more accurately considered to be part of the global South than the global North.

\[^4\] I am generalizing my title for the simplicity of the narrative. More specifically, I was a physiotherapy student during my time in Malawi and identified myself as such. I did not have registration to practice in South Africa and did not have an opportunity to do so in Cameroon, so instead considered myself to be a “physiotherapy researcher” in those places. Clinical practice was a notable part of my roles in Haiti and the Mushkegowuk Cree territory, therefore I actively and typically identified myself as a physiotherapist.
negotiating its use granted me access onto a slippery terrain of shifting insider and outsider statuses. Furthermore, it taught me that as difficult as it is to learn a language, it is possible, and when one does learn a language the rewards can be significant. My interest in languages combined with my interest in the particular to extend the way I interact in and with a place. Prior to beginning this thesis, I attained fluency in Haitian Creole and Spanish, and developed various levels of basic function in a number of others.

2.1.5 Positionality as applied to the research field

Here I synthesize the characteristics, perspectives, and experiences that guide my interests and interactions. This combination influences not only the places that I go and the things that I do when in those places; it can also influence how people respond to my presence, and how I respond to their responses. These characteristics, perspectives, and experiences are therefore important to methodological and logistical choices that affect study design, but also to the social contexts that are created as I engage in research.

My socio-political interests (postcolonialism, equalizing opportunities, limiting consumptivism, and challenging capitalism) are direct contributory factors to my interest in this research in disability in the global South. I approach this work from the standpoint of social justice and sustainability. I come to these values in protest to my upbringing, and yet embody the values of being active and achieving, also carried forward from my upbringing. I bring to this work specific interest in language and the particular, with the intent to learn to know a place and a people in-depth. It is likely because of these factors that I sought to conduct fieldwork off the beaten path (see also Section 2.2.2), together with research participants experiencing multiple axes of oppression (Morgan, 1996).

Given the above interests, I engaged in a research field with multiple dimensions of privilege (Morgan, 1996) as compared to the research participants. There is reason to believe that for the participants, my nationality and race were clear and immediate signs of privilege, wealth, and influence. I anticipated that these characteristics would affect my interactions with participants. My gender, lack of apparent disability, and age (an adult man, but not an elder) were likely less
important than nationality and race, but still relevant with respect to my interactions. My status as a post-secondary student might have simultaneously flagged me as a person with opportunities, but also as a person who was limited in means at the time of the research.

2.2 Approach

2.2.1 Interest in collaboration

In presenting the approach I have taken to this research, I am making explicit key choices that I made in early stages. These choices had downstream consequences.

In my previous postcolonial encounters, I had sought to create collaborative relationships with the supposed beneficiaries of the services in which I was working. In found I that these intentions were difficult to fulfill, possibly as the result of the established norms of relations between those who provide services and those who receive them. A more common dynamic seemed to be one where employees in positions of power (often from the global North) made decisions, and beneficiaries acted and reacted to these. My experience observing these dynamics were that the re/actions of beneficiaries seemed to be subjugated silence, orchestrated deference, and occasionally antagonism. Because of these experiences, I approached my thesis work with the intent to privilege opportunities for participation and partnership as expressions of collaborative relationships. To improve the possibilities of doing this, I opted to build upon the existing research relationships of one of my co-supervisors, Dr. Stephanie Nixon, in Zambia.

Dr. Nixon’s closest relationship with the Zambian disability community was with the Zambian Federation of Disability Organisations (ZAFOD). This civil-society organization brings together 12 national disabled persons’ organizations, each one focused on a given disability (e.g., Zambian National Association for the Deaf), a given demographic (e.g., Zambia National Association of Disabled Women) or a given issue (e.g., Zambia Association on Employment for Persons with Disabilities) (ZAFOD, 2015). My interaction with ZAFOD was beneficial to me in helping me to learn about disability issues in Zambia and in connecting me to other stakeholders, such as the governmental agency for persons with disabilities, and ZAFOD’s active provincial offices.
2.2.2 Geographic preferences

In previous experiences in the global South, I had noticed marked within country differences with respect to standard of living, poverty, access to services, and culture based on geography. These differences were primarily based on urban/rural status, but also on large cities as compared to small, and the relative fertility of various rural areas. By noting this observation here, I do not mean to create additional hierarchized binaries – the inequality and inadequate infrastructure of so-called “prosperous” areas can lead to different, but equally pressing, challenges – but I do mean to make explicit that I identified this as a dynamic. Moreover, I have noticed a pattern where health researchers are not able to (or choose not to) spend significant time in outlying areas. Furthermore, my interest in the particular pulled me towards communities with strong traditional cultures and smaller populations that I could learn about more comprehensively.

The within country differences noted above, a desire to conduct research in locations where other researchers do not go, and an interest in the particular, converged to create a geographic preference for me to conduct this research in small cities and/or rural areas. This preference informed my activities from a very early stage in the research design process: I approached my networking and learning with the intent to identify a small city and/or rural area as a research site. In a following section on Research Context (Section 2.3), I describe Zambia and the research sites in greater detail, but first describe the pathway that I followed to reach these sites.

2.2.3 Time in Zambia

To conduct this thesis, I made four trips to Zambia, spending a total of 13 months in the country. My first trip was three weeks’ duration in March 2012, accompanied by Dr. Nixon in order to meet some of her research partners and get a feel for the national capital of Lusaka. In 2013, I returned for a three-month period (June-September) in order to establish my own connections and build the contextual awareness needed to develop the thesis proposal. I spent the majority of this time in Lusaka learning about institutional structures and studying Zambian languages, but also traveled to other areas. It was during this period that the Federal Director at ZAFOD, Ms. Sarah Brotherton, suggested that I connect with the ZAFOD office in Mongu, Western Province.
Through the ZAFOD Provincial Coordinator in Western Province, Mr. Oscar Lwiindi, I developed a network of contacts and some baseline understanding of the province’s geography and culture. I discuss the geography and culture of Western Province in Section 2.3.2, but briefly, this jurisdiction matched my pre-established criteria of being more outlying with strong traditions and few foreigners from the global North. Although my first connections to Western Province were in 2013, it was in 2014 that it (temporarily) became home. By early 2014 I had developed my research proposal and spent two months in Lusaka reinforcing my network there, seeking ethics and administrative approvals (see Appendices 11 and 12), and logistically preparing for fieldwork. In March 2014, I moved to Mongu and used this city as a base until August 2014. I describe the fieldwork conducted in this period in more detail in Chapter 3 (Methodology and methods).

Having come from an action-oriented background in service provision and service development, I approached this project with the concern for practical action mainstreamed into the design. One practical way of mainstreaming this concern was by embedding an action-oriented return trip to Zambia into my overall timeline. During the fieldwork period, I pledged to participants that I would return to engage in action activities in “early 2015.” My specific plan was an action-oriented trip of three months’ duration beginning in January 2015. This plan was modified since the early analysis phase unfolded more slowly and frustratingly than I had foreseen (see Chapter 6). Upon reaching the previously-identified timeframe for the return trip, it was apparent that I was not in a position to engage in an action component. In response to this reality, I adjusted my trip from three months to six weeks (mid-March to end-April, 2015). I split this time between Lusaka and Western Province, using it to maintain a connection with my contacts and research participants, and as an opportunity to re-engage some of my research assistants.

2.3 Research context

2.3.1 Zambia

Zambia is a country in southern Africa with a population of 13.1 million people in 2010 (CSO, 2012b). In 2010, 60% of the population lived in rural areas and 40% in urban areas (CSO, 2012b), with many of the urban dwellers concentrated in the large cities along the line of rail
through the central-west part of the country. Cities away from the line of rail are often smaller commercial and administrative centres. Zambia has a central government and is currently divided into ten provinces.

Economically, Zambia is considered to be a lower middle-income country by the World Bank (2016). Since colonial times, Zambia’s economy has been most heavily influenced by the copper mines located in the Copperbelt and North-Western Provinces.

Zambia has a history of cultural and linguistic diversity, with 73 officially recognized ethnic groups. Although English is Zambia’s official language, seven other major languages are accorded special status for education, literacy campaigns, and information dissemination (CSO, 2012b, p. 64). Despite this, in the post-independence era there has been significant migration of individuals and families (Ferguson, 1999) such that the major cities include peoples from a mixture of backgrounds, communicating most-widely in a limited number of lingua franca languages. For many, life in Zambia’s large urban centres shares commonalities to that of other large cities across the world. Conversely, in the small cities and rural centres linguistic and traditional cultures are stronger.

With respect to disability, Zambia’s governmental jurisdiction of disability is primarily through the Zambian Agency for Persons with Disabilities (ZAPD). This agency is nested within the Department of Social Welfare, which is itself nested within the Ministry of Community Development, Mother and Child Health. In the legal sphere, Zambia has a Persons with Disabilities Act (Government of Zambia, 2012). Through civil society, the Zambian Federation of Disability Organisations is a federated organisation that brings together twelve disabled persons’ organizations representing multiple disability types, demographics, and interests (ZAFOD, 2015).

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5 Some indigenous languages have developed what some call “town” forms (see Gray, Lubasi, & Bwalya, 2013). These urban vernaculars are quickly evolving, modifying according to the influence of English and other indigenous languages. Nyanja and Bemba are the most common town languages in Zambia.
Western Province

Western is one of Zambia’s ten provinces, and has a population of 900,000, about 85% of whom live in rural areas. Western Province is currently subdivided into 16 districts. The 16 district arrangement is relatively recent phenomenon: the result of a subdivision process in which nine new districts were spliced off from the pre-existing districts (Ministry of Local Government and Housing, n.d.). At the time of the research, the newly-created districts were still early in the process of developing their district offices and services and therefore not yet operational.

Districts are further subdivided into wards. The provincial capital of Western Province is Mongu, which has a population (approximately 50,000 people) more than twice the size of the next largest centre.

Western Province is the traditional homeland of the Lozi people and was granted a special status by the British colonial rulers due to a treaty signed in 1900 (Gluckman, 1968, p. 13). In addition to its jurisdiction under the national government of Zambia, the traditional leadership structure of Western Province is governed through the hierarchical Barotseland Royal Establishment (World Fish, n.d.). According to the 2010 national census, just over 50% of the provincial population is ethnic Lozi (CSO, 2012b). The next largest single group is the Mbunda, an ethnic group that has had members migrating eastward from modern-day Angola to Western Province in a process that began in the 19th century (Barrett, 2003). People of Mbunda ethnicity constituted 15% of the provincial population in 2010 (CSO, 2012b).

Western Province’s strong links to tradition and small city/rural demography made it a desirable area for me to conduct the research, once I made my connections with the ZAFOD provincial office. Within Western Province, this research took place in two sites: Mongu Town and an outlying area of Kalabo District. I describe the process of selecting those sites when discussing participant recruitment, in Section 3.2.3.

Mongu Town

This municipality is nested within the larger Mongu district. As the provincial capital, Mongu is a centre for administrative and business activity. The town is connected by paved road and
regular public transport access to central (i.e., Lusaka) and southern (i.e., Livingstone) part of Zambia. Mongu has multiple business districts with markets and shops, regular electricity, and many paved roads within town. The town’s density fades away at the fringes as urban areas cede to peri-urban areas where many residents still engage in agricultural activities. The study research site was in one of these peri-urban areas, with most residents living in walking distance of a paved highway.

2.3.2.2 Kalabo District

Kalabo is an overwhelmingly rural\(^6\) district across the Zambezi floodplain from Mongu. At the time of the study, the form of travel to Mongu depended upon the height of the floodwaters with travel by boat in the flood season (approximately January-June) or shared taxi crossing the river by ferry in the dry season (approximately July-December). During this same period, a causeway-bridge mega project was under construction to link Mongu and Kalabo by year-round paved road. This road is being built to extend to the border with Angola.

The pre-existing district of Kalabo extended to the international border with Angola, but the district is now buffered from the border by the newly-created district of Sikongo. Because of the proximity to Angola, Kalabo has a reasonably high percentage of people of Mbunda people, in addition to Lozi, and other ethnicities with smaller populations. The research site in Kalabo was in an outlying ward (i.e., away from Kalabo Town, which in itself is a much smaller centre than is Mongu). In this area, there were neither paved roads nor access to the electrical grid. There was a religious mission in the community that had a small hospital and there was an elementary school and market near the main road. A sizeable village spread between the mission and the school/market area. Away from the sizeable village, there were smaller villages which shared the civic connections of the hospital, school, and market.

\(^6\) In 2010, 97.4% of the population of Kalabo District lived in rural areas (CSO, 2012a, p. 3)
2.4 Concepts

Here I describe the ways in which I approach a number of key concepts in this thesis, specifically, (1) disability, (2) strategies to improve the situation of persons with disabilities, and (3) the categorized world.

2.4.1 Disability

The phenomenon of disability was central to this study, but was intentionally not conceptualized prior to fieldwork, to allow space for a more indigenous or co-constructed understanding of disability. Instead, the initial conceptual grounding was premised upon the investigation of locally circulating phenomena that might be similar to “disability,” as recognized by a global Northerner. I began this investigation with the insight of Oscar Lwiindi, the ZAFOD coordinator in Western Province, and his counterpart at the Zambian Agency for Persons with Disabilities provincial office. The mere existence of these local branches suggested the possibility that there might be a broadly accepted local understanding of disability.

I continued the process of conceptually approximating disability in the local context by evaluating language. To do this I asked myself the question: do people in Western Zambia speak of concepts that are roughly comparable to disability? Indeed, they do, there are two words in the dominant regional language of Silozi used as conglomerate terms that are roughly equivalent to the English word disability. These words were buhole and buyanga. Through the fieldwork phase of this study, the research assistants and I referred to the study as one that was being conducted with people who experienced disability (or more often, buhole and buyanga). The people with whom we were speaking then used those words according to their own meaning. In the urban setting, there were groups that had been established to unite people who experience buhole and buyanga. During data generation activities, the participants used these two words interchangeably. It was locally understood in Western Zambia that some elements of life were systematically different for people who experienced buhole and buyanga as compared to those who did not. This issue is discussed in more detail in Chapter 4.
2.4.1.1 Groups united around the issue of disability / Disability groups

Participants in this study were conceptualized as individuals, but also as groups. As collective entities, groups seemed more likely to be culturally relevant with respect to the research questions. It was also suspected that the groups would be the main source of collective identity with respect to disability issues. Furthermore, the groups are likely offer greater collective strength than that of individuals, which could in turn increase the probability for participatory research.

Recognition of the value of groups to disability organizing dates back to the United Nations (1994) Standard Rules on the Equalization of Opportunities for Persons with Disabilities. This type of group is often referred to as a “DPO” – a disabled persons’/peoples’ organization (Ncube, 2005). In Zambia, two types of DPOs are recognized by law: “organizations for persons with disabilities” and “organizations of persons with disabilities” (Government of Zambia, 2012). The distinction between these two rests on the disability status of the individual members, with organizations “of” having a majority of members with disabilities.

Like the approach I used to conceptualize disability, I strived to allow the concept of groups to emerge in the local context, without any presumptions with respect to the disability status of members. In planning the study, I used the notion of “groups united around the issue of disability” as the main participating unit of interest; I describe my strategy to identify eligible groups in the Methods section of this thesis (Section 3.2.3.1). I intentionally avoid using the term DPOs and those recognized by Zambian law in order to demonstrate my broader inclusion criteria and openness to new formats. The makeup of the participating groups is described in the results section of Chapter 4 (Section 4.3). In order to make my references to these groups less cumbersome, I typically refer to them as “disability groups.”

Despite my interest in collectives, I was concerned that by presuming its supremacy, the study would be unable to draw upon the contributions of individuals. Examples of these contributions are the ways in which individual members could influence the collective, or be lost within it. By simultaneously conceptualizing the participants as individuals, there remained a space for
participants to speak and act individually, and report on meaningful activity with other collectives (such as their family or village).

2.4.2 Strategies to improve the situation of persons with disabilities

This thesis is premised on the idea that things can be done to improve the situation of persons with disabilities, irrespective of their current situation (good, bad, or otherwise). In order to explore these, I have identified the concept of strategies to improve the situation of persons with disabilities. In the thesis, I refer to these as strategies for the purpose of brevity. In the design of the study, I considered strategies that were either pursued with the explicit intent of improving the situation of persons with disabilities, or happened to improve their situation, regardless of the intent.

In addition to the overall definition, I also conceptualized the strategies according to the agency that was responsible for them: initiatives were strategies created by persons with disabilities to improve their own situation. Activities and services were both initiated by outside bodies (e.g., government agencies and non-governmental organizations), but could involve the active participation of persons with disabilities (activities), or could be run exclusively by others for the benefit of persons with disabilities (services). The categories of initiatives, activities, and services were never intended to be discrete nor exhaustive, but instead 1) serve as a way to facilitate discussion among participants, and 2) increase the probability of identifying strategies done by persons with disabilities, rather than only thinking exclusively of those done for them.

Although I used the terms initiatives, activities, and services, in the recruitment and consent (Appendices 4-6) and data generation (Appendices 7-9) processes, I discovered that the distinctions did not resonate in the field as the research participants spoke in ways that differed greatly from my conceptualization (see Chapter 6). Ultimately, the notion of strategies was robust and informative in the research project (see Chapter 5), although the specifications of initiatives, activities, and services were not.
2.4.3 The categorized world

It is common practice in many disciplines, and in society more generally, to re/create categories of places and peoples. In this thesis I predominantly refer to “the global South” and “the global North,” due to the influence of postcolonial disability studies (e.g., Grech, 2011) and global health, two fields in which this terminology is common. Here, I refer collectively to places and peoples who have experienced colonial occupation and its negative ongoing effects as the global South. Geographically, the global South covers most of Africa, Asia, and Latin America. The counterpart to this is the global North, covering the parts of the world that generally benefit from the postcolonial arrangement. The global North includes former imperial powers (e.g., France), but also the dominant populations of settler colony nations (e.g., Canada).

The categories of globals South and North provide a useful lens to allow us to see postcolonial dynamics, yet they are also laden with complications. Here I focus only on those complications that I see as the most glaring. First, although these are geographic categories, they are not always consistent with their nominal cardinal directions: I consider Australia to be part of the global North despite clearly being in the Southern Hemisphere, and Kazakhstan and Mongolia to be parts of the global South despite being rather northerly countries. Second, these terms are often used to categorize entire nations, when nations occupy a liminal status or have stark exceptions within them. The People’s Republic of China is a contemporary example of a nation-state that could be considered either global North or South depending upon the criteria of analysis. The systematic occupation and subjugation of indigenous peoples by the dominant population of Canada has created a situation where many First Nations reserves meet the definition of the global South. Judd and DeBoard (2009) surmount these complications by referring to “the cosmopolitan setting,” by which they refer collectively to the majority populations of wealthy nations and the wealthy urban elite of poor countries. Unfortunately, *cosmopolitan* is likely more of a risk for additional confusion than it is an opportunity for clarity, given that the term is generally used in another sense (Kant, 2006, as cited in Popke, 2007).

There are other categorization systems that operate similarly to globals South and North, regardless of the logic of their design. *Periphery* and *metropole* were already mentioned as
examples from postcolonial studies. Low- and middle-income countries (LMICs) are a common signifier in global economics (in contrast to high-income countries, HICs). Western is a common identifier used in discussions about knowledge systems, whereby Europeans saw their systems and culture as superior to that of Orientals, a derogatory term used to collectively signify North Africa, the Middle East, and Asia. Western knowledge is occasionally termed colonizer knowledge, and presented in contrast to indigenous knowledge. I use the identifier of global South for consistency, even where peripheral, indigenous, or LMICs might be more consistent with the literature supporting a given argument. Likewise, I use global North, even in situations where metropole, colonizer, HICs, and Western might be used more commonly.

Given the inequalities of the postcolonial world, the creation of categories to capture larger phenomena is a useful tool to understand global dynamics. These categories are social constructs that can be useful analytic tools, but they all have particularities, limitations, and come with the risk of reinforcing the notion of a homogenized “other.” I have premised this study on the existence of a postcolonial world with a global North and a global South because there really are patterns of economic and epistemological domination that are patterned on the ongoing legacies of colonialism (Connell, 2011; Smith, 2012). I use this premise with the intent to make visible these legacies and contribute to the resistance to them. Despite this, I realize the danger of reinforcing the notion of a categorized world that is static and absolute. For this reason, I emphasize that although there are elements of common experience that allow us to identify a global South, there is also significant diversity.

2.5 References


Chapter 3

3 Methodology and methods

In this chapter, I describe the methodology and methods in a comprehensive fashion. The methodology and methods of this thesis are also described in each of the manuscript chapters (Chapters 4 through 7). In having drafted manuscripts for publication as individual entities, the focus of each manuscript chapter is narrower than that of the larger thesis, therefore the discussion of the methodology and methods is also narrower. There is repetition between manuscript chapters: some details are required in each standalone manuscript, which in turn means that they must be repeated. Conversely, this chapter includes details that were not described in the individual manuscripts due to space constraints and direct relevance to the manuscripts.

3.1 Methodology

Methodology refers to “the abstract theoretical assumptions and principles that underpin a particular research approach” (Grant & Giddings, 2002, p. 12). Here I build upon the foundations, commitments, and critique that I have presented in Chapters 1 and 2, to identify the scientific principles that I used to guide the research.

3.1.1 Constructionism

This research was centrally grounded in a constructionist methodology. Silverman (2006) refers to constructionism as “a model which encourages researchers to focus upon how phenomena come to be what they are through the close study of interaction in different contexts” (p. 400). Constructionism was an appropriate methodology for this study because of its encouragement of focus on interaction and on context.

Substantively, an important aspect of this research has been to challenge framings of disability from the global North that are applied indiscriminately in the global South. In order to meet this challenge, I sought ways of gathering the perspectives of persons with disabilities in the global South, such that these can inform a new, expanded, and different style of knowledge base.
However, in a constructionist approach it is recognized that in seeking these perspectives, I am still part of the knowledge generating equation. Constructionist methodologies account for this dynamic in their epistemological base, understanding that knowledge claims are co-created between participants and researchers, rather than existing independent of human intervention and waiting to be discovered by researchers.

Constructionism, as used in this project, is a good fit with postcolonialism in that it encourages the interplay of voices from the North with those from the South to produce hybrid forms of knowledge that might overcome hierarchical binaries. The concept of hybridity has been a point of contention among postcolonial scholars (Ashcroft, Griffiths, & Tiffin, 2007) with critics pointing to a naïve neglect of power differentials and the racist historical connotation of the term. Although constructionism has origins in colonizer epistemology, even in the counter-perspective of decolonizing methodologies there is space for the colonized to welcome useful aspects of science from the global North (Smith, 2012). Constructionism fits this mold by offering a fusion, but there are additional, complementary, elements required in order for this methodology to work for this project.

### 3.1.2 Participatory research

As stated in Chapters 1 and 2, I approached this research with a goal of collaboration with the supposed beneficiaries of the research. I made specific reference to participatory research in addition to constructionism because it goes beyond constructionism’s recognition of co-construction and explicitly attempts to change the dynamics of knowledge generation. In participatory research, relationships must be actively fostered and managed, and the benefits of the research constantly considered.

I am looking at participatory research as a broad paradigm. There are specific articulations of participatory research such as participatory action research (PAR) and community-based participatory research (CBPR), among others (Herr & Anderson, 2005, p. 2). I have not used any specific articulation for this research. Despite the multiple specific interpretations that make up
this paradigm, all are consistent with respect to meaningful participant engagement and an action-orientation to the research (Sclove, 1997).

3.1.3 Critical social science perspective

Although participatory research challenges the researcher to think about the inter-personal relations between researcher and the researched (often blurring the boundaries between the two), it tends not to demand a more sophisticated interrogation of the knowledge creation process. In order to devote more specific attention to the process of knowledge creation, I also used a critical social science perspective (CSSP) as described by Eakin, Robertson, Poland, Coburn, & Edwards (1996). A CSSP encourages the researcher to adopt “a ‘reflexive’ posture towards knowledge and the research process” (p. 158) in order to identify the patterns of knowledge creation that systematically benefit some people(s) to the detriment of others. The CSSP identifies several key features to guide researchers, namely: assumptions and ideology; the influence of overt, subtle, and covert forms of power; contradiction; and the dialectic between structure and agency.

A CSSP is coherent with constructionism in that both begin with the principle that knowledge is socially constructed. Furthermore, the CSSP shares consistent values with participatory research, proposing that “engaging research ‘subjects’ in setting research objectives…might embody the spirit of a CSSP.” The CSSP and participatory research both compel researchers to recognize and change the knowledge creation process, but they do so with slightly different areas of emphasis. In designing this study, I have granted attention and weight to the focus of both participatory research and a CSSP in order to incorporate the complementary aspects that each of these offers.

3.2 Methods

According to Grant and Giddings (2002), “methods are the practical means, the tools, for collecting and analysing data” (p. 12). Here I describe the specific methods that I used to build and manage the research team, recruit participants, and generate and analyze data.
3.2.1 Research team

I led this project as doctoral candidate and principal investigator, with the advisory support of my thesis committee members. The project was carried out with the support of a team of five paid research assistants (RAs) local to Western Zambia. The role of the RAs evolved over the course of the project according to the research priorities and my assessment of the availabilities and competencies of the staff members. The initial concern that stimulated the hiring of the RAs was English-Silozi translation, a necessity in this transcultural research project in which I did not have the necessary language skills. From this foundation, I discovered that each RA had a unique skillset and situation. Given the evolving situation in the field, I negotiated the tasks of each RA in an ongoing fashion to maximize their contribution to the project, their development of useful skills, and their personal fulfillment.

The RAs are described individually in Table 3.1. In the table they are identified by name and initials, facilitating the more detailed description of roles here. One of the RAs (PK) was promoted to the role of “Research Assistant Coordinator” due to the exceptionally high quality of her work, leadership skills, and full-time availability over the course of the project. Three of the RAs (PK, MLM, LAN) were involved with the project through the duration of the fieldwork period and both of the fieldwork sites. Two of the RAs were involved with only one of the two sites (AM, Mongu-only; KC, Kalabo-only). All RAs were hired through recommendations, with three (MLM, LAN, AM) recommended by the University of Barotseland, where they were all full-time undergraduate students. The two other RAs (PK, KC) were not employed at the time that I hired them as RAs, but each one had work experience with non-profit organizations and had completed a post-secondary diploma through a district trades training institute.

The RAs were paid a daily wage through the project budget. The project budget also paid for travel expenses for fieldwork activities, including food and accommodations expenses for activities that lasted an entire day or multiple days.
<table>
<thead>
<tr>
<th>Name (initials)</th>
<th>Resident of:</th>
<th>Recommended by:</th>
<th>Responsibilities</th>
<th>Approximate number of hours worked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patrah Kapolesa (PK)</td>
<td>Mongu</td>
<td>Dept. of Social Welfare</td>
<td>New employee supervision, logistical planning, oral &amp; written translation, transcription</td>
<td>840</td>
</tr>
<tr>
<td>Miyanda Lastford Malambo (MLM)</td>
<td>Mongu</td>
<td>University of Barotseland</td>
<td>Written translation, transcription, IT &amp; data management systems</td>
<td>450</td>
</tr>
<tr>
<td>Lynn Akufuna Nalikena (LAN)</td>
<td>Mongu</td>
<td>University of Barotseland</td>
<td>Oral &amp; written translation, transcription</td>
<td>300</td>
</tr>
<tr>
<td>Aongola Mwangala (AM)</td>
<td>Mongu</td>
<td>University of Barotseland</td>
<td>Written translation, typing, transcription, administrative activities</td>
<td>150</td>
</tr>
<tr>
<td>Kashela Chibinda (KC)</td>
<td>Kalabo</td>
<td>Research colleague</td>
<td>Logistical planning, oral &amp; written translation, transcription</td>
<td>180</td>
</tr>
</tbody>
</table>
3.2.2 Research assistant training, standards, and review

All RAs participated in paid training sessions conducted by me prior to engaging in productive work activities. The purpose of these initial training sessions was to ensure that all RAs understood the research project’s goals and methods and were aware of the expectations for their work. Initial training sessions focused on written and oral translation, including my expectation for conceptual equivalence (Squires, 2009). In striving to attain conceptual equivalence, we devised a shared project vocabulary in which we modified our use of both English and Silozi in order to use terms and phrases which were essentially equivalent in both languages, while ensuring that these equivalent terms and phrases were easily comprehensible in each language.

When I established that there was sufficient translation capacity to conduct the data generation activities, I turned my attention to other skills, including the discussion of participant consent, data management and storage, and transcription. All RAs were trained in this basic skillset.

Ensuring quality in transcription was of particular importance for the research process. In order to ensure that the transcripts 1) captured all of the audible speech, and 2) accounted for any discrepancies in oral translation, the RAs and I collectively devised a transcription guide, which we revised twice over the course of the project (see Appendix 1). Using this document for guidance, we employed a standardized procedure in which a minimum of two transcribers would contribute to a given document, and the evolving transcript was saved at numerous stages to ensure a paper trail of the process. While still in the field, I verified the first series of completed transcripts to ensure their quality, using my observations to inform revisions to the transcription guide and an improvement in transcription quality.

I performed a performance review with each RA in order to discuss my impression of their work and their perspectives of the experience. A blank performance review sheet is presented in Appendix 2. We used these performance reviews to modify tasks according to a collective assessment of the process-to-date. At the completion of the work term, each RA received a letter confirming their employment in this project and highlighting positive aspects of their performance (see Appendix 3 for an example).
3.2.3 Recruitment

Participants in this research were drawn from two sites: one in the Mongu urban area, another in a rural area of Western Province. As explained in Section 2.4.1.1, at each site, the participants were conceived in two simultaneous ways: (1) as a disability group and (2) as individual members within the disability group. The inclusion criteria are identified below; they were created to reflect the diverse urban and rural circumstances of Western Province. The process of making contact differed according to site; each is described in turn. In each case, I used a two-stage recruitment process that was implemented according to the unique circumstances of the group.

3.2.3.1 Inclusion criteria

Groups were considered eligible for this research if 1) they had a collective identity, and 2) members of the collective generally agreed that the group existed because of a common interest in disability.

For the determination of collective identity, I used the following three questions to guide eligibility:

1. Is there a sign of collective identity such as the group referring to itself by a name?

2. Are there external forms of recognition (e.g., being listed on a registry, possibly by the local government, traditional leadership, or a disability agency)?

3. Are there established rules of order (be they formal or informal) that govern the conduct?

Individuals were considered eligible for this research if they: 1) were members of a participating community, and 2) consented to participate in the study.

3.2.3.2 Making contact: urban site

During the fieldwork preparation trip of 2013, I learned that there were approximately 35 disability groups in the Mongu area that were registered by the Zambian Agency for Persons
with Disabilities (ZAPD) provincial office. The ZAPD provincial coordinator reported that he had initiated this registry system in order to help persons with disabilities access opportunities. Through the registry initiative, there was supposedly a standardized size (ten members) and structure (chair, secretary, treasurer etc.) for disability groups. Shortly after my arrival in Mongu to begin fieldwork (March 2014), I contacted the ZAPD provincial coordinator (retired by that time) for a suggestion of groups to contact. He suggested two that seemed to be functioning well and provided contact information for each. From this initial contact, I was able to pursue the standardized two-stage recruitment process that I devised with the first group (described below in Section 3.2.3.4).

3.2.3.3 Making contact: rural site

In 2013, I learned that the disability group registry did not extend into the rural areas, but that there were collective initiatives of various sorts throughout the province. During my visits in 2013, I lacked research ethics board approval that would allow formal recruitment and I had insufficient travel time to visit rural areas. Due to these realities, I designed this study uncertain of the nature of disability groups in rural areas, but with the intent to identify groups upon my return for fieldwork in 2014.

In March 2014, I consulted the Department of Social Welfare provincial office in order to access their network of district offices. Upon the suggestion of the provincial office, I visited two district offices (Shangombo and Kalabo) through three-day fieldtrips. During these trips I discovered that in Shangombo there was no existing group known to the District Social Welfare office, but there were persons with disabilities who were interested in forming one to participate in the project. I also discovered that Shangombo was a long trip from Mongu over a dirt road, typically requiring 12 hours of travel without certainty that one would complete the trip on a given day. In Kalabo, the District Social Welfare office was familiar with a cluster of persons with disabilities that was located approximately one hour’s travel from the town. Travel time to Kalabo town from Mongu depended upon the height of the flood and the operations of boats and shared taxis, but was typically less than four hours. I opted to pursue the two-stage recruitment process with the cluster of persons with disabilities in Kalabo.
3.2.3.4 Two-stage recruitment process

In order to account for group-level and individual-level concerns in recruitment, I devised a two-stage recruitment process, whereby I sought to 1) establish group interest, prior to 2) seeking individual consent. Each of these is described in turn.

3.2.3.4.1 Stage 1: Establishing group interest

Establishing group interest began with a letter to the group leaders to describe the research (see Appendix 4) and meetings to discuss the groups’ potential participation. The expectation was that the groups would use their typical decision-making mechanisms to determine their collective interest, prior to approaching individual members.

In the case of the urban group in Mongu, there were two meetings. In the first meeting, I met with the Chair, who was receptive of the research and invited me to join the group’s regularly scheduled meetings to discuss their involvement. It was at this second meeting that the group agreed in-principle to participate and we began to arrange the first data generation activity.

In rural Kalabo, I met the cluster of persons with disabilities by attending a pre-scheduled meeting that had been arranged with the District Social Welfare Officer. I spoke about the research process at this meeting and multiple attendees declared that the research should happen. The District Social Welfare Officer was accustomed to dealing with the cluster as a whole, and not specific leaders, so at this meeting we discussed the group’s structure and leadership. There was no one at the meeting who could identify the precise membership numbers, but these were estimated to be “a few dozen.” A group of that size was larger than the size for which I had designed the study, yet it seemed manageable. The leadership was originally identified to be eight people, and the group insisted that all of these leaders should be involved in the discussion and the planning of the research. Given the prospective size of the group and the layout of the community, it was suggested to me that the group be divided in half with subgroups to the east and to the west of the main road. Dividing the group into two based on geography seemed acceptable to those present and would reduce travel distance to study activities for the group members. From this first meeting, I arranged follow-up meetings with leaders in the east and in
the west (four leaders each). During these follow-up meetings, the leaders confirmed their groups’ interest in participating in the study and we began planning the first data generation activity.

3.2.3.4.2 Stage 2: Approaching individual members

Each of the members of the disability groups was approached individually in order to discuss their participation and establish their consent to participate. These conversations about participation and consent were supported by the participant information sheet and consent form, each of which was available in Silozi and English (See Appendices 5 and 6). I conducted a small number of these conversations (typically with the help of an RA for translation), while the RAs conducted the majority with supervision.

The specific process used to approach individual participants varied according to circumstance. For the urban group (Mongu), we held the conversations about participation and consent prior to the first data generation activity (a focus group discussion) since there were four RAs available and I felt that this strategy would maximize efficiency. I found that this strategy was functional, but that the conversations took a long time and delayed the start of the focus group discussion. As a result of this experience the RAs and I changed strategies for the rural group (Kalabo), visiting as many group members at home as our schedule would allow. This strategy was onerous and entailed the establishment of consent for group members whom we never saw again, but significantly streamlined the first data generation activities.

3.2.3.5 Participants

In the urban group, 22 of 24 registered members participated in at least one data generation activity. Of the two urban group members who did not participate, one was a man with a hearing impairment whose schedule precluded involvement. The other was a woman with a physical disability who lived a long distance from the Chair’s home and was generally considered an inactive member.

In the rural group, 59 members participated in at least one activity. The structure of the rural group precluded a definitive membership count (see Chapter 4 for more details).
The majority of participants were adults who had disabilities and engaged as self-representing disability group members. A small number of participants were represented by parents and guardians (some of whom had disabilities themselves). The participants who were represented included children with disabilities and adults with communication difficulties that precluded their direct participation. From the urban group, two older teenagers with physical disabilities (16 and 17 years of age, respectively) and one adult with an intellectual disability participated together with a parent.

3.2.4 Data generation

In this thesis I use the term *data generation* rather than *data collection* so that the constructionist methodology of the study is explicitly recognized (Silverman, 2007). According to constructionist methodology, researchers are attentive to the way in which data are created through interaction in a context (Silverman, 2006). In this sense, the data were co-constructed through interactions in which both the researcher and the participants contributed. The data generated for this thesis were qualitative. These data included audio recorded and transcribed 1) focus group discussions with the disability groups and 2) individual interviews with disability group members, as well as 3) participant observation fieldnotes.

When referring collectively to the focus group discussions and individual interviews, I refer to *data generation activities*. I wrote fieldnotes after data generation activities that captured my observations, as well as after other activities in which I participated with the disability groups (e.g., planning and preparation meetings). All data generation was consistent with a constructionist methodology, and designed to incorporate collective and individual activities. The data generation activities were all semi-structured and arranged to begin with more general content and progressively move to more focused content. I led all data generation activities with the support of a translator. All data generation activities were audio recorded and transcribed by the RAs using the process described in the transcription guide (Appendix 1). The overall framework of the data generation process was designed to allow the groups opportunities to influence the project-related activities as the study progressed, incorporating the engagement element of participatory research into the data generation process. Below, I provide an overview
of the data generation process and then discuss each of the data generation activities in greater detail.

3.2.4.1 Overview of data generation process

Data were generated for this research in three waves of data generation activities. The first wave was a focus group discussion (or multiple focus group discussions, depending on the circumstances). The second wave of data generation activity was a series of individual interviews. The individual interviews were spread out over an extended period. During this same time frame, there were also mid-point meetings with each of the groups in order to collectively assess the project up to that point and plan the final fieldwork activities. The third wave of data generation activity was a final focus group discussion (or multiple focus group discussions, depending on the circumstances). The specific format and participant numbers of data generation activities are presented in Table 4.1 (presented as part of Chapter 4 in order to match the text from that manuscript).

With each group I also initiated follow up activities. In the case of the urban group, the follow up activity was a series of meetings with local traditional leaders that resulted in the group being granted a plot of land. With the rural group, the RAs and I participated in a banquet that was funded through the project budget but organized by the group leaders.

3.2.4.2 Round one focus group discussions

This data generation activity was designed to establish rapport with the groups and to explore meanings of disability and strategies to improve the situation of persons with disabilities. The focus group discussion was guided by the semi-structured tool that was created for that purpose (see Appendix 7). All focus group discussions were associated with a mid-day meal, in which all participants (disability group members and researchers) were welcome to share.

In the urban group, I initially prioritized the opportunity to assemble all participants for a data generation activity, and therefore held only one first round focus group discussion. The focus group discussion was held in the home of the Chair, the same location that the group typically used for their meetings. The participation numbers, the size of the venue, the time taken for
conversations about participation and consent, and the overall schedule of the day combined to complicate this focus group discussion. Ultimately, the large number of participants could not all fit in the house with some participating from the porch outside the doorway. Since the conversations about participation and consent had taken longer than foreseen, the focus group discussion began later than planned, and the impending mid-day meal was a notable distraction through most of the focus group discussion. Although I had planned the activity to approximate *the usual dynamics* of the group, I learned through this exercise that this intention was contrived: regularly-scheduled group meetings were attended by fewer members and did not include a shared meal. Learning from this experience, I planned all future focus group discussions according to the smaller numbers suggested for bilingual focus groups in the global South (Maynard-Tucker, 2000).

The rural group had a larger number of people wanting to participate than I could comfortably accommodate. See Chapter 4 for more details about the precursors to this situation, and my adaptations to it. With the large numbers of participants, the proposed division of the group into east and west sub-groups, and the experience from the urban group, I prepared a schedule of four focus group discussions. In each of the east and west, there would be a morning focus group discussion and an afternoon focus group discussion; with each participant to attend one of the two. Between the two focus group discussions was the mid-day meal, shared with all participants. In preparing for the rural round one focus group discussions, the RAs and I had conversations about participation and consent with some group members in the days prior to the actual activities. This practice attenuated the challenges of the round one focus group discussion days, yet we were still overwhelmed by the high numbers of people wanting to participate. Given the project’s capacity for data generation, and my growing awareness of the fluid nature of the rural group, I adjusted future data generation activities to focus on sub-sets of participants identified from the round one focus group discussions.

### 3.2.4.3 Individual interviews

This data generation activity was designed to further build rapport with study participants and to provide opportunities for group members to speak as individuals separate from their respective
groups. These interviews were guided by a semi-structured interview guide created specifically for this purpose (see Appendix 8), and further informed by the participants’ comments from the round one focus group discussion in which they had participated. The interviews were conducted in a convenient location in which the participant felt comfortable. For most participants this location was in their home or just outside of it, but for one participant the interview was conducted under a tree, within sight of the oranges she was selling by the roadside.

With the urban group I attempted to interview all members, and ultimately completed 20 interviews with 22 members (in two cases I interviewed two family members together). With the rural group I reviewed the participation of group members in the round one focus group discussions and purposively selected 19 members with whom to conduct interviews.

### 3.2.4.4 Round two focus group discussions

The round two focus group discussions were designed to be more focused, with the discussion oriented towards strategies to improve the situation of persons with disabilities with which the participants were likely to be familiar. These activities were still semi-structured, with probing questions for each strategy as (see Appendix 9). The lists of actual strategies that were discussed were created from a review of the round one focus group discussions, the individual interviews, and strategies I had become aware of in my time in Mongu and Kalabo.

The urban group was divided into two for this round of focus group discussions, with half of the group participating before the mid-day meal and the other half participating after. With the rural group, I came to understand over the course of my fieldwork that the most clearly bounded group was the leaders, including the eight who were originally identified, and one other who came to my attention during the preparation and data generation activities. These nine leaders were invited to the final focus group discussion, although two were not able to attend due to competing commitments.

### 3.2.5 Data analysis

All data had been entered into Microsoft Word documents while in the field; with the audio files of the data generation activities transcribed and the fieldnotes typed. Neither the participants nor
the research assistants were involved in data analysis. I conducted all data analysis activities with the support of my thesis committee. Data analysis was conducted in two broad stages: 1) analysis of the data generated in the field in order to address the research questions, and 2) reflexive analysis of the research experience. I address each one of these broad stages in turn.

3.2.5.1 First stage of analysis: objectives 1 and 2

Objective 1: To describe the unique context and nature of one urban and one rural disability group in Western Zambia, and explore these groups’ expressed concerns.

Objective 2: To explore how strategies to improve the situation of persons with disabilities are framed within the accounts of participating disability groups in Western Zambia.

This first stage of data analysis was focused on the study’s empirical objectives. This stage was informed primarily by the principles of thematic analysis as described by Braun and Clarke (2006) and content analysis as described by Hsieh and Shannon (2005). I approached the first stage in three steps: (1) re-familiarizing myself with/immersing myself in that data, (2) creating and using a code book, and (3) evolving the analysis into manuscripts.

In step one of this stage of analysis, I re-familiarized myself with the data, as suggested by Braun and Clarke (2006), by reading through all of the transcripts while listening to the audio files. Through reading the transcripts and listening to the audio files, I was immersed in the data and had a sense of its whole (Hseih & Shannon, 2005). I conducted step one beginning with the round one focus group discussions for each group and moving forward in time through the individual interviews and then finishing with the round two focus group discussions.

I made improvements to the transcripts during step one, correcting spelling mistakes and format errors while adding text that had been otherwise omitted. When speech in English did not appear on the transcript, I transcribed it directly. When speech in Silozi or Chimbunda did not appear, I copied down the maximum that I could grasp and noted the sections of transcript and audio file. Step one was also an opportunity to review language, allowing me to identify translations that seemed incomplete or inconsistent. I reviewed all of the translation issues and missing Silozi and
Chimbunda speech with research assistant Patrah Kapolesa when I was in Zambia in March 2015. Together we resolved these issues such that the transcripts matched the audio files to the standards outlined in the transcription guide (see Appendix 1).

In step two, I performed the initial coding. From the experience of step one I developed an initial code book. This initial code book was based upon a combination of questions used to direct the data generation and others developed by reading through the transcripts (see Appendix 10). I then coded all transcripts and participant observation fieldnotes according to the structure of the initial code book and the general principles of directed content analysis (Hsieh & Shannon, 2005). I performed this step using NVivo 10 for Windows7.

In step three, I used an iterative process to evolve the analysis into manuscript form. I used the experience and NVivo node summaries of the initial coding to organize the emerging ideas into new written and diagram forms, according to objectives 1 and 2. One example of an early written form is presented in Appendix 11. An example of an early diagram form is presented in Appendix 12. Through an iterative process of writing progressively more-detailed documents, creating diagrams, and re-organizing textual data into additional codes I evolved the ideas into two manuscripts (Chapters 4 and 5). In Appendix 13, I present the evolution of the manuscript ideas into Chapters 4 and 5.

### 3.2.5.2 Second stage of analysis: objective 3

Objective 3: To critically reflect on the experience of conducting this thesis research through the lenses of (a) a critical social science perspective (CSSP), and (b) global health research ethics, in order to better understand the research process.

The second stage of data analysis was focused on the study’s reflective objective. Through the first stage of analysis, it became apparent to me that the results of the research were evolving in different, more uncomfortable, directions than I had foreseen. First, the process was taking

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7 NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012.
longer than the time I had budgeted in my thesis timeline, creating a mismatch between the time that I had pledged to return to Western Zambia and the time needed to generate action-oriented results to share with the stakeholders for my planned returned (as described in Section 2.2.3). Second, I began to realize that I had designed the project with a very different conception of results than I was actually producing. I had foreseen that I would be able to use my results to create a written document discussing strategies, describing those that were operational, identifying gaps, and outlining the aspirations of persons with disabilities. Instead, my results were of a completely different nature: I was finding that disability and the strategies to improve the situation of persons with disabilities were socio-economic. The socio-economic orientation of the results somehow felt wrong (see Chapter 6) despite the fact that I had been careful to ground my analysis in the data and the apparent coherence between understandings of disability that emerged and the strategies to address it.

The discomfort of the first stage of analysis created difficulties, but also created further analytic opportunities. My discomfort with respect to the socio-economic orientation of the results incentivized additional reflection back to the fieldwork and allowed me to identify disjunctures (Mandel, 2003) between my expectations and the experience of research. I reflexively analyzed those disjunctures to develop the manuscript presented in Chapter 6. My realization that the involvement of the participants and the action-orientation of the thesis had progressed in a different way than foreseen incentivized me to use the recently-developed Principles for Global Health Research (CCGHR, 2015) to reflect on research practice, as it occurred in this thesis. These experiences and my reflections seemed of importance and hence were developed into the manuscript presented in Chapter 7.

### 3.3 Ethical considerations

The ethical considerations for this research transcended the research approach, methodology and methods. The research was premised on postcolonialism which is, in-and-of itself a normatively derived entity considerate of equity and justice. These concerns were carried through the assumptions and principles of critical approach and participatory research, each of which centralizes concerns about power. The research was also guided prospectively by concerns over
global research competencies, as identified by Cole et al., (2011). This research was further linked to global health research ethical concerns through a post hoc reflection on the research process, using the Principles for Global Health Research (CCGHR, 2015) (see Chapter 7).

This study also included specific steps throughout the process to ensure ethical conduct. The study was approved by the University of Toronto Health Sciences Research Ethics Board (Appendix 14), the University of Zambia Humanities and Social Sciences Research Ethics Committee (Appendix 15), and the Zambian Ministry of Health (Appendix 16).

Groups and participants were recruited to this study through a two-stage process in order to ensure interest from groups and consent from individuals. This process was systematic and transparent to reduce the possibility of tension within larger communities (e.g., from individuals and groups considered to be in competition with the participants). To reduce travel burden for participants, the locations of study activities were carefully selected, including the conduct of individual interviews in or near the participants’ homes. When travel was necessary for study activities (meetings or data generation) participants’ travel costs to study activities were paid when there was motorized transportation available for hire. Meetings and focus group discussions were planned multiple days in advance to allow participants to plan their schedules, whereas individual interviews were approached spontaneously to ensure that participants did not spend the day waiting at home for researchers arriving on an unpredictable schedule. The burden of participation in focus group discussions was compensated with a mid-day meal, whereas participation in meetings called for the purpose of research was compensated with a snack and a drink.

All study data were stored securely as per University of Toronto procedures to protect the identities of participants. This included the use of a locked container storied in a locked location for paper data and the use of encrypted media and a secure website for electronic data. All RAs were trained in the principles of basic research practice, including the need for consent, confidentiality, and secure data storage practices.
To maintain the anonymity of participants, they are identified in the written data through an alpha-numeric code rather than their actual name. Actual names were used in the data generation activities, and are therefore present in the recorded audio files. Everyone involved with data generation activities referred to others according to their actual names, as opposed to coded unique identifiers, so that the activities would be more similar to typical interaction, involve less risk of mistaken identities, and avoid ableist practices (e.g., using a visible sign to represent a codified identify of participants in groups with members with visual impairments). Therefore, the anonymization of data from the focus group discussions and interviews occurred at the time of the transcription of the audio files. In the fieldnotes, participants are identified through their alpha-numeric codes. The alpha-numeric codes which were stored in a separate electronic file from the transcripts and participant observation fieldnotes. Participating individuals and groups are identified in this thesis in general terms to allow the reader to understand their situation without revealing the identity of the participants.

3.4 References


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8 Participants knew each other prior to the data generation activities, making it easier to refer to each other through actual names, and much more difficult to use a coded unique identifier accurately and consistently.


Chapter 4

Disability research in Western Zambia: “All of the problems of poverty are brought because of being disabled”

This manuscript was submitted to *Disability & Rehabilitation* (1 March 2016).

Cleaver, S., Polatajko, H., Bond, V., Magalhães, L., & Nixon, S.

Abstract

**Purpose:** To contribute to the pluralistic knowledge base of disability through the study of a specific culture and context in the global South. Specific objectives: (1) describe the unique context and nature of one urban and one rural disability group in Western Zambia, and (2) explore these groups’ expressed concerns.

**Method:** Participatory research strategies and a critical social science perspective informed this constructionist qualitative study. Data generation focused upon life with a disability and services available to the disabled. Data were generated through 39 interviews and eight focus group discussions with 81 disability group members.

**Results:** The urban group was formally-structured while the rural group was fluid. Each of these was a contextually-specific arrangement to increase the likelihood of the groups accessing resources. The groups’ main expressed concern was poverty. Their concern was expressed in terms of a life of suffering and a need for material resources.

**Conclusions:** Poverty was inherent in the experience of disability in the study’s context in Western Zambia. This context was influenced by the co-constructed nature of data generation, but not limited to it. This study increases pluralistic knowledge of disability in the global South and informs strategies to improve the situation of the disabled.
Disability research in Western Zambia: “All of the problems of poverty are brought because of being disabled”

4.1 Introduction

Disability in the low- and middle-income countries of the global South is said to have been misunderstood and misrepresented by academic and international development actors [1,2]. This scenario is considered to have occurred, in large part, due to the misconception that the global South is a homogenous entity where disability can be understood through a series of reductionist explanations. These reductionist explanations include the “myth of the hidden disabled” [3] and the indiscriminate lumping of numerous diverse peoples as a singular category of “traditional societies.” Using the singular categorization of traditional societies, non-Western beliefs about disability are narrowly linked to supernatural curses. Disturbingly, even documents that are considered to be global in origin and scope reduce a plurality of diverse cultures into “traditional societies” [e.g., 4].

The presentation of disability as a homogenous entity in the global South creates a space for the belief that the well-being of persons with disabilities can be improved by uncritically importing concepts from the global North. Among these imported concepts are “inclusion,” a notional sense of rights, and a narrowly conceived community-based rehabilitation [5,6]. Although the importation of these concepts is likely linked to some examples of progress, it is also linked to situations in the global South where scarce resources have been used for programs that were ineffectual [5,6]. Worse yet, in some cases these imported concepts might have even undermined existing structures that support people who experience impairment and disability [7].

There is an active and conscious alternative to this status quo; one that does not presume a homogenous experience of disability and therefore takes interest in the varieties of experiences that exist across cultures and contexts [8]. A number of researchers have contributed to this alternative by studying the understandings of disability in different contexts of the global South [9-12]. This research has contributed insight about the rich and pluralistic experience of disability and added these insights to the body of legitimized scientific knowledge. From the platform of scientific knowledge, these insights can be made available to inform research and practice that is different from the homogenizing status quo.
Despite the important contributions of this research to understandings of disability in the global South, the studies of this phenomenon thus far [9-12] have been designed with the foundational premise that the researcher is an observer [13]. With this foundational premise, it is not possible to see the ways in which the presence of the researcher impacts the research field. In situations where a researcher is coming from a different environment, it is possible that their mere presence could impact the ways in which people speak of disability. If the researcher is seen by the participants to be a person of privilege, then this possibility could be more likely to occur.

The purpose of this study is to contribute to a more pluralistic knowledge base of disability in a specific culture and context of the global South. In practical terms, the study was developed upon a pre-existing partnership between researchers in Canada and disability civil society groups in Zambia. Upon the advice of the Zambian partners, the research was based in the country’s Western Province. The specific objectives of this study were (1) to describe the unique context and nature of one urban and one rural group united by disability in Western Zambia, and (2) to explore these groups’ expressed concerns. Central to the design of this research is the awareness that the researcher’s involvement is one of co-construction, not passive observation.

4.2 Methods

4.2.1 Study design

The study was guided by a qualitative constructionist methodology [14] with participatory [15] and critical considerations [16]. It is accepted in qualitative constructionist methodology [14] that researchers and participants co-construct meanings. The essential features of the study were developed by the first author and his thesis supervisors (described below), with additional insight provided by national-level Zambian disability advocates. Participants were invited to influence the conduct of the research to an increasing extent as the study progressed. The key features of a critical social science perspective as described by Eakin et al. – reflexivity, assumptions and ideology, power, contradiction, and dialectic [16] – were an ongoing consideration through the study process, influencing the study framing, design, data generation, and analysis.

4.2.2 Study context

The research fieldwork was conducted in Zambia’s Western Province between March and August 2014. Western Province is considered the country’s poorest and least developed
province. This area is the traditional homeland of the Lozi people. Prior to the colonial interruption, the Lozi had developed an elaborate economy based upon fishing, agriculture and cattle-herding on the rising and falling waters of the Zambezi River on the Barotse floodplain [17]. In modern Western Province, there are a number of ethnicities, but Lozi language (Silozi) and culture predominate in the population of approximately 900,000 inhabitants [18]. Approximately 85% of residents live in rural areas while the remainder are spread throughout towns and the provincial capital of Mongu [18]. The main economic activities for people in Western Province – including city and town-dwellers – are subsistence fishing and farming supplemented by small trade.

4.2.3 Study team description

The first author is a PhD student researcher and rehabilitation professional from Canada, supported by a supervision team of senior academics comprising of three rehabilitation researchers from Canadian universities and an anthropologist based at a research institution in Zambia. The study activities were supported through the work of five paid research assistants who were post-secondary students from Western Province.

4.2.4 Sampling and recruitment

The study team purposively sought to recruit two groups united around the issue of disability (one urban and one rural) to participate in this research. Sampling groups as opposed to individuals permitted insight into disability organizing, allowed for a more indigenous view of disability by relying on pre-existing structures, and increased the likelihood that this research would complement ongoing initiatives. The decision to seek groups ‘united around’ disability was made to increase the probability of identifying eligible groups in this exploratory study and to permit an openness to a wider variety of structures in-place, yet the intent was to give preference to “organizations of persons with disabilities” [19]. The inclusion criteria for the groups were: 1) having a collective identity or a form of recognition as a group, and 2) general agreement among members that this group exists because of a common interest in disability.

To identify these groups, contacts from local government offices shared connections with one group in a peri-urban neighbourhood of Mongu (urban) and another in a series of villages in an outlying district (rural). The contact for each of these groups began with a request for a meeting.
with the leadership in order to discuss the group’s potential participation in the research. In both cases, the leaders agreed that participation was in the interest of the collective. The first author and research assistants then approached members individually to discuss the research objectives and design, and their individual participation. Consent was obtained with each participant during a meeting with a research assistant in a language of the participant’s choice. Collectively, the research assistants were fluent in multiple Zambian languages that participants were likely to use locally on a regular basis, allowing the study team to allocate an assistant according to the participants’ preferences. The key message of this meeting with the research assistant was that the purpose of the research was knowledge generation for practical purposes – such as informing the advocacy efforts of the groups – and not the direct provision of resources to individual participants or the disability groups.

4.2.5 Data generation

For each group, data was generated through an initial round of focus group discussions, followed by semi-structured individual interviews with a number of the group members, and then a second round of focus group discussions. Data generation activities were premised upon a gradual relationship-building process, structured to include both group and individual activities, and designed to minimize the extent to which the phenomenon of disability was defined by the researchers prior to entering the field. The first round of focus group discussions and the interviews were based upon questions about life with a disability, supported by probes about the positive and the negative aspects of life as it relates to disability. The second round of focus groups included discussion on specific activities, services, and initiatives that were available in the communities where participants lived.

These activities were led by the first author. The first author participated in these activities by speaking English. Participants spoke the language of their choice, which was typically not English. Since the first author did not speak the local languages well, a research assistant performed real-time translation. All data generation activities were audio-recorded. Research assistant team members transcribed all speech in all original languages according to a comprehensive transcription guide developed by the team.
4.2.6 Data analysis

Data analysis began with a detailed review of all transcripts by the first author while listening to the audio files, an activity that shared similarities with Phase 1 of thematic analysis (Familiarizing oneself with the data) recommended by Braun and Clark [20]. The detailed review was used to guide an iterative analytic process, where initial ideas were used to inform subsequent questions of the data. This iterative analytic process was informed by the conventional and directed content analysis approaches described by Hsieh and Shannon [21]. Questions and answers generated during the iterative analytic process were transformed into visual schematics and written documents in order to further organize ideas and eventually distill the themes presented in this paper. Visual schematics and written documents were shared with the supervision team to generate further discussion and reflection as part of a process to gradually refine the analysis.

4.2.7 Ethical considerations

This study was approved by the University of Toronto Health Sciences Research Ethics Board (Appendix 14), the University of Zambia Humanities and Social Sciences Research Ethics Committee (Appendix 15), and the Zambian Ministry of Health (Appendix 16). To reduce the burden of participation, participants’ travel costs were paid when there was motorized transportation available for hire, and a group meal was provided for large meetings and focus group discussions. Participating individuals and groups are identified in this manuscript in general terms to allow the reader to understand their situation without revealing the identity of the participants. Ethical practices in this research were also informed by critical [16], post-colonial [1,2], and global health principles [22] that consider the well-being and agency of participating communities with collective interests and concerns, and recognize that academic research is conducted within a dynamic of power relations.

4.3 Results

This study set out to describe the unique nature and context of two disability groups in the Western Province of Zambia, and to explore the groups’ expressed concerns. First, the in-depth descriptions of the two groups united around the issue of disability are presented. The analysis of the participants’ expressed concerns is then presented in the second part of the results section.
4.3.1 Groups united around the issue of disability

4.3.1.1 Urban group

The urban group was first identified by a local government official in Mongu who offered a connection to this structured and formally-recognized entity. This urban group had been founded two years prior and had 24 members (13 men and boys; 11 women and girls) who were considered to be disabled by either themselves or their family members. The group identified its members according to their own self-described categories, as follows: physical disabilities (13 members), mental retardation (4), deaf and dumb (3), visually impaired (2), hearing impaired (1), and Down syndrome (1). These individuals reported ages ranging from 11 to 71.

The planning of data generation activities with the urban group was initiated through contact with the chair who arranged a formal meeting with ten of the group members. The activities are identified with the numbers of participants in Table 4.1. Seventeen of the 24 group members participated in data generation activities themselves, although two of these participants (a deaf woman and a teenage girl) each completed their interviews with the support of a family member. Another five (four children and a deaf man) were represented by family members due to intellectual or communicative impairments that could not be overcome with assistance. Two group members did not participate in data generation activities despite multiple attempts to make contact. In the urban group, data were primarily generated in Silozi, but also in English (verbal and written), and American Sign Language to a lesser extent.

4.3.1.2 Rural group

To address the difficulty of locating a rural group, a government agency in Mongu contacted its district offices, one of which was aware of a group of persons with disabilities in an outlying ward where there had previously been a leprosy treatment centre. The district office arranged for the first author and research assistants to meet with nine individuals (seven men and two women) who were considered leaders among this group. In contrast to the structured group in Mongu, the rural group was unstructured and fluid in the sense that there was no definitive and ongoing distinction between who was or was not a member, yet both the leaders and the government officials insisted that this was indeed a group. Through the initial communications, the unstructured and fluid aspects were challenging for the first author and research assistants. Whereas the study team expected the leaders to be able to provide a list of members, the leaders
Table 4.1 – Participants and data generation activities

<table>
<thead>
<tr>
<th></th>
<th>Urban group</th>
<th>Rural group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Round 1 Focus group discussions (FGDs)</strong></td>
<td>1 FGD – 18 participants</td>
<td>4 FGDs&lt;sup&gt;a&lt;/sup&gt;:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A – 16 participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>B – 12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>C – 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D – 15</td>
</tr>
<tr>
<td><strong>Interviews</strong></td>
<td>20 individual interviews with 22 participants</td>
<td>19 individual interviews&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td><strong>Round 2 Focus group discussions (FGDs)</strong></td>
<td>2 FGDs&lt;sup&gt;d&lt;/sup&gt;:</td>
<td>1 FGD – 7 participants&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>A – 10 participants</td>
<td></td>
</tr>
<tr>
<td></td>
<td>B – 8</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Due to the large number of people wanting to participate, the rural group was subdivided according to four areas of residence for the first focus group discussion; each person participated in only one FGD, and the nine leaders are spread among the four FGDs.

<sup>b</sup> In two cases there were two family member participants who agreed to be interviewed together. For this reason, there were 20 interviews but 22 participants who completed an interview.

<sup>c</sup> The 19 interviews were conducted with nine group leaders and ten participants purposively selected based on their participation in the Round 1 FGD.

<sup>d</sup> Due to crowding in the round 1 FGD it was decided that the round 2 would be more comfortable if the participants were divided into two groups.

<sup>e</sup> The round 2 FGD in the rural group was only conducted with the leaders of the group. Seven of the nine leaders participated.
requested clarification about who should be considered disabled. With each party confused by the other’s approach, the number of invitees for the round one focus group discussions was in constant flux. The ultimate number was determined primarily by the capacity of the venues, with 50 “other members” (17 men and boys; 33 women and girls) accommodated in addition to the leaders. The specific numbers of people included in the data generation activities are presented in Table 4.1.

Most of the 59 people in the rural group described their disabilities as being physical in nature, although there were a small number who reported visual or hearing impairments. Like the urban group, there were some family members who participated in the study activities on behalf of a child, or on behalf of an adult with a severe disability that rendered participation difficult. Participants in the rural group reported ages between 6 and 87 with many reporting “elderly” instead of a specific age. In the rural group, data were primarily generated in Silozi (verbal and written), but also in Chimbunda and Makoma, to a lesser extent.

4.3.2 Participants’ concerns

The second objective of this inquiry was to explore the concerns of one urban group and one rural group united around the issue of disability. Our analysis showed that the accounts of the participants were dominated by a concern with poverty. This single theme was expressed by participants through the interconnected phenomena of a need for material resources and a life of suffering. The relationship between these concepts can be conceptualized as a coin, where the coin as a whole represents poverty, with the one side of the coin representing the participants’ narratives of suffering as part of a life with disability, and the other side of the coin representing material resources that were needed but were not available (see Figure 4.1).
In the accounts of the participants, it was the lack of material resources (money or things that could be purchased with it) that was responsible for the suffering, and an influx of material resources that would alleviate the suffering. As stated by a woman in the rural group with a physical disability due to leprosy, “Since my disability has found me, there has been no one to build me a house, there is no one to find me food, there is nothing. Who will help me with this suffering?” A man in the urban group with a physical disability emphasized the improvement in life circumstances that would come with an influx of material resources: “Like for me the way I feel, if I find someone giving me money. I will see that I have been helped and then they can improve my life.”

Participants presented the concern of poverty as inherent in their experience of disability. Participants initially presented their disability in very similar terms to the specific embodied state of having an impairment. They then linked this state to ‘the poverty coin’ in patterned ways. Two of these patterned ways were 1) impairments impeding resource acquisition, resulting in suffering, and 2) the poverty as an integral part of the experience of disability.

4.3.2.1 Impairments impede material resource acquisition, resulting in suffering

In many of the participants’ accounts, the link between impairments, a lack of material resources, and a life of suffering was described as a series of causal steps. Often, the situation involved only one step, where an individual’s impairment reduced employment opportunities or the ability to farm for food or income. As stated by a man in the rural group with physical and communication
impairments: “We are really living in poverty. Like the others have said, when there is work, we people who are disabled cannot do it. Even when you try to go there, they will tell you, ‘You, you cannot do it.’ And that is really the truth, that you really cannot.”

Another participant from the rural group spoke about how his physical impairments limited the activities that he could do and his compensation from these activities:

Like for me I cannot say ‘I can go and cultivate, I can go and fetch water, or I can go and do this.’ Because even this [wheelchair] in which I am seated, I need to find someone push it. But God has given me the knowledge of how to repair shoes. But again, if a request a certain price to say ‘maybe I can manage to buy a cup of flour or something, so that I feed myself,’ [the clients] refuse also. Now them, they want to be able to choose how much to give me. Because they know that I have no option there is no way I can refuse their money, and that ‘I can give him this money’ because they know am disabled I have no option, I just have to accept the amount.

In some cases, it was the impairments of children that kept the parents at home. These limited opportunities to acquire or generate resources are thus the primary and direct explanations that underlie the participants’ lives of suffering. A mother of a child with a severe disability in the urban group gave an example of this when she expressed, “I cannot do a business which will need me to walk or travel to go very far, leaving [my daughter]. I can’t leave her.”

Participants spoke of how an infusion of resources (money or things that could be purchased with it) could offer an alternative path to success without requiring any change to their own specific impairment. For example, a gift of a sewing machine would allow income generation in the home so that the mother quoted above could simultaneously care for her child with a disability while earning money to eliminate suffering and therefore overcome the problems of poverty.

Another example of this phenomenon came from a woman in the urban group with a physical disability. This woman spoke about how she had previously purchased fish and then traveled with it elsewhere in the country to re-sell it at a profit. Since she had used the money to pay for school fees for a child, she no longer had the money to generate income. Nonetheless, the participant was confident that her fortunes would change with monetary support: “Right now I do not have the money; if I did I would have gone even a long time ago [to the flood plains to buy fish].”
In other cases, there were multiple steps separating the current situation of poverty with an aspired situation of wealth and freedom. An example of this was a woman with a physical impairment who was limited in her capacity to walk, which reduced her income generating capacity, which in turn inhibited her from being able to amass capital to start a business which would provide further income to pay for a return to school to study to be a professional. According to this woman’s account, a positive cycle could have been activated through loans or grants of money or materials that would have allowed her to start the business.

4.3.2.2 The poverty coin as an integral part of the experience of disability

In other accounts, the relationship between a lack of material resources and suffering was not a series of connected steps, but one where disability was integrally understood to apply to individuals who simultaneously experienced an impairment and the two-sided poverty coin. When invoking this pattern, participants spoke of poverty and disability interchangeably, as if they were using two synonymous words to describe a single phenomenon.

In attempting to tease apart notions of wealth and disability, participants were asked about situations where someone was disabled but wealthy, or did not have a disability and was poor. Participants responded with disinterest or apparent confusion to these questions, providing answers that did not seem to match the question.

One example of this phenomenon occurred during a focus group discussion with the urban group. The members were speaking about the difficulties of life with a disability. One man with a physical disability in this group added:

> What I have seen in life is if you are disabled but you are working, you are doing a business, people will respect you for that. For you who doesn’t have anything and you are disabled, you are poor. No one can respect you, even the family members can’t respect.

From the quote above, it might seem that disability and poverty could be teased apart, such that being disabled while doing a business would be a respectful scenario. In order to probe more deeply into this, the following exchange occurred:

> Interviewer: You said that people, even if they have a disability, if they have a business they get respect and people who do not have businesses cannot get respect. Did I understand that correctly?
Participant: Yes it is.

I: Ok, in that case I would like to find out how things are different for persons with disabilities who own businesses as compared to people without disabilities who own businesses?

P: We differ because some people, maybe when they come to visit you if you are doing a business you will be able to give them something but if you do not have a business which you are running even when they ask you something you cannot give them anything because you do not have, so you are not regarded…All [of the problems of poverty are] brought because of being disabled.

As is seen from the account above, the notions of disability and poverty can be expressed and understood in nearly interchangeable terms.

In the account of another participant with a physical disability in the urban group, disability was again interchangeable with poverty and it was inconceivable to lose the poverty-alleviating benefits of participation in a disability group:

Interviewer: If starting tomorrow everyone forgot that you are “a lame person,” but nothing else changed, would your life be the same or would it improve?

Participant: Ah, on that way I was going to be grateful because maybe this mocking is coming because of what I have or what I do not have because of being poor. But if they see me that, “that person this time has got this, he is able to do this,” they will give me respect.

I: Ok, all right. If starting tomorrow everyone forgot that you were lame, then I am not sure you could still be a member of the Disabled Association. So on one side if the people didn’t think of you as having a disability, you might get more respect; but on the other side, you would lose the reason to be together with those people there. If that happened, would it still be a good thing or it could actually be a bad thing for you?

P: Someone cannot move out of that group because that’s where we are finding the very big help.

In the account of this same participant, the notion of self-help groups for people without disabilities was not a topic of interest:

Interviewer: Your neighbors who do not have disabilities, do they form groups or other things to…to try to make their voices stronger?

Participant: I cannot answer that question because I do not know how they are living.
As is seen from these examples, it was as if it was only the disabled who could be poor. Meanwhile, being rich (i.e., doing a business) was the categorical opposite of being disabled, and the challenges of and approaches to poverty among people who were not disabled were not phenomena of interest for the participants.

When participants spoke of poverty as being integrally part of disability, it seemed taken for granted that the co-existence of needs and the inability to meet them were the defining elements of being a person with a disability. The proposed solutions were therefore gifts of material resources in order to directly meet their needs.

4.3.3 Examining the two sides of the coin of poverty

4.3.3.1 The back side: a need for, and a lack of, material resources

In this paper, the term *material resources* is composite, encompassing 1) money or 2) items and services that can be purchased with money. In Table 4.2 there is a list of examples of material resources that participants presented in the context of discussing life with a disability and specific activities, services, and initiatives that were potentially available. In many instances the participants spoke of particular items (e.g., a new house, fertilizer, hair dryers), whereas in others there was discussion about money, and how items could be purchased if a person had access to money.
Table 4.2 – Material resources that participants stated they did not have and/or needed

<table>
<thead>
<tr>
<th>Tangible items</th>
<th>Services and expenses that could be covered if they were granted money</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food rations</td>
<td>School expenses</td>
</tr>
<tr>
<td>Hair dryers</td>
<td>Tap costs</td>
</tr>
<tr>
<td>Sewing machines</td>
<td>Investment in a business</td>
</tr>
<tr>
<td>Fertilizer</td>
<td>Human resources to pay wages for</td>
</tr>
<tr>
<td>Fishing supplies</td>
<td>Firewood collection</td>
</tr>
<tr>
<td>Goods for resale</td>
<td>Cultivation</td>
</tr>
<tr>
<td>Mill (the machine)</td>
<td>Fishing assistance</td>
</tr>
<tr>
<td>Certificates of recognition</td>
<td></td>
</tr>
<tr>
<td>Food and drink for visitors</td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td></td>
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</tbody>
</table>

Some material resources were presented as items the participants needed for their own personal use, such as better housing or food rations (i.e., bags of flour for the staple meal). As stated by a participant in a focus group discussion with the rural group, “For me the only problem is my eyes. But I need someone to help me. There is no one to build a house, so what I want is just help from you. And you give me food.”

In other cases, the reference to the resource was with respect to its utility in earning more income. As stated by a woman with a physical disability in the urban group when asked about the positives of having a disability in a focus group discussion “I am even talented on hair styling. I am a hair stylist. I can [braid] any type of a style for hair any type that a person wants. I can do it, but I don’t have money to start my own salon.”

For this woman, having a salon meant renting a market stall and purchasing some hand-held hair dryers – modest investments, but ones that entailed more money than she currently had. At the conclusion of the individual interview, when the first author asked if she had any questions, her one question was “So it’s not possible to help me with money to open my own salon?”
Occasionally, participants were ambiguous as to whether the resources would be used for personal use or as income generation. Examples of this last phenomenon included those where participants spoke of needing money to pay an individual to collect firewood, cultivate a garden, or assist with fishing. This is exemplified by a participant from the urban group who was blind, stating:

[Before I contracted cerebral malaria] I was able to cultivate or plough with my own hands but these days I cannot see. I was able to go fishing, paddling [a canoe] in the canals, but now I cannot. I can do these things if I have someone [to help me]. And that person needs to be paid. But where am I going to get the money?

Participants spoke of material resources as things that were highly desirable or necessary, but also as things that they did not have and were unable to acquire given the circumstances. There were various strategies used to advance this topic of discussion. In some cases, the participants simply declared that a resource was needed or desired. In other cases, participants discussed not having something (or enough of something) and how this was a problem. In still other cases, participants spoke positively of a scenario where they had received resources in the past or could potentially receive them in the future.

One example of an account celebrating past instances where material resources were distributed came from a man in the rural group with multiple physical impairments due to leprosy. He described, in great detail, the story of a foreign missionary who had formerly lived in the rural community, but had collected money in his country of origin in order to provide various forms of charity:

In each place [the missionary] asked for one person who is educated who will be writing the report... and writing the names of people who were living in poverty…Now he gave the order to say ‘These people now you should build houses for them these people who do not have one. A house and a kitchen and a fence.’

4.3.3.2 The front side of the coin: a life of suffering

The implication of the participants’ frequent references to a lack of material resources was generally expressed as a life of suffering. Suffering was described in numerous ways, in particular as a lack of food and the presence of hunger, and as an inability to provide comfort and opportunities for one’s children.
4.3.3.2.1  Food and hunger

Many participants spoke of a lack of food and the associated hunger. Some described their personal situation as one of severe deprivation. As was articulated by a woman from the rural group living with her granddaughter (both with physical disabilities) in response to a question about their general state of affairs:

Life is just the way that you have found us: there is only hunger. The little maize that we were given by [a local government office] is nearly finished. Today is our last meal. Tomorrow [my granddaughter] will go to school with an empty stomach.

For some of these participants their only source of food was charity, receiving this from “well-wishers” whom they knew or as special initiatives from local service agencies. On occasion these participants would include other elements of basic needs as part of their accounts, referring to their houses that leaked in the rain and their clothing that was limited to what their neighbours had shared.

Other participants spoke of the need for additional food in less urgent terms. An example of this was a man with a physical disability in the urban group. He spoke of the need for the group to be supplied with income generating resources such as farm animals or equipment “So that the profit, we can find help...buying food for ourselves.” Members in both urban and rural groups spoke of an expectation that government agencies would supply them with more food, although typically without specifying whether this was to meet urgent needs, to supplement their diet, or to reduce food costs to free up money for other purposes.

For one participant in the urban group, the family’s food consumption, together with clothing, seemed to be an important indication of their social standing with the neighbours. He was concerned that his children would appear poorly-fed and poorly-clothed, and that the cause of this situation would be traced back to him, as a breadwinner of a lower calibre due to his physical disability.

This situation, although less dire and more social in nature than physical, demonstrates a different kind of food-related suffering that was still important for participants.
4.3.3.2.2 The inability of parents to provide comfort and future opportunities

A number of participants spoke of well-being in terms of the future, and related this to the costs of education. One example of this was from a man in the urban group with a physical disability who had taken a number of orphans into his household. In the context of him explaining that he had little money, he stated that there was a need for someone “to contribute to their education so that they can also find their life as they grow up.”

Costs related to education were expressed in various forms. For older children, the costs were fundamental, with a lack of tuition and exam fees blocking the students at the doors of the school. As a woman in the urban group with a physical disability stated, “My son is supposed to be in Grade 12 right now but I do not have money to pay for him.” In the case of a younger student with a physical disability, in Grade 8 at the time, the costs were more related to school items. As explained by her mother, “Things like bags and all things which were needed by the school she does not have, because for me, I cannot support her.”

For one family, the associated costs of school converge with issues of current comfort and future well-being in a single account. As explained by the mother of a boy with an intellectual disability in the urban group, the schools nearby will not accept him into the classroom, forcing him to stay at home where he is teased and beaten up by others in the neighbourhood. Meanwhile, there are various other schools in Mongu that will take him, but these are far away from home. She explains:

\[
\text{It is so difficult because you can find a place at [a number of schools] but for transport it is very hard. If you ask a taxi driver, the taxi driver will be saying, ‘You will be paying 50 kwacha [USD $8] every day for taking and bringing you back.’ Seeing the way we are, I am not going to manage.}
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4.3.4 Summary of results

This study was co-constructed with two very different groups of persons with disabilities in Zambia’s Western Province. The most important difference between the groups was with respect to group structure: the urban group was formal and concrete, whereas the rural group was informal and fluid. With both of these groups, the main concern was poverty. Participants spoke of poverty in terms of the inter-related issues of material resources and a life of suffering.
4.4 Discussion

This study is the first in the peer-reviewed literature to contribute to a more pluralistic knowledge base of disability in a specific culture and context of the global South with an active recognition of the co-constructed nature of the data. This study can make important contributions towards the many challenges faced by persons with disabilities in the global South [23] in at least two ways. First, it can disrupt the neocolonial arrangement whereby powerful actors rely on homogenizing views of disability to impose conditions upon the peoples and institutions of global South [2]. Second, this study can inform new arrangements by presenting an alternative understanding of disability to academics and international development actors.

4.4.1 Groups united around disability

The awareness that this study was a co-construction created a space to view the context and the nature of the participating groups as a window into the situation of persons with disabilities. The two groups differed significantly with respect to nature, which is understandable given their different contexts. However, the two groups also differed with respect to the way that they interfaced with the study.

The urban group’s formalized structure had been developed as one group among many in Mongu in response to an initiative from a local government employee. This structure had been rewarded through subsequent governmental initiatives, and was also congruent to this study design. The rural group’s fluid nature had developed over many years due to a variety of influences including a religious mission and multiple government offices, although there could be others yet. The fluid nature of this group increased its adaptability to match the pre-determined initiatives of diverse and unforeseen visitors. Conversely, the fluid nature was in conflict with the design of this study: a foundational principle of this study was that grassroots disability organizations should be able to structure themselves for their own purposes and according to their own vision.

Important insight can be drawn from the description of these groups as part of this study’s co-construction. The first is that the apparent differences in the structure of these groups are underwritten by a common drive for material resources. In the case of the urban group, their concrete structure had facilitated the receipt of food rations and won them equipment. Members of the rural group spoke about instances where they had formed a group in the past, other
instances where they had not needed to, and their willingness to form a group again. The commonality of all of these accounts from the rural participants was that they related to securing resources. In effect, the past and current activities of these participants is very consistent with their primary expressed concern: poverty.

The second insight from the description of the groups relates to the production of knowledge about what disability is in a given culture and context. The original conceptualization of this study was premised on the notion that an indigenous understanding of disability would inform the eligibility for group membership. Membership eligibility could then be used as one way to understand who would be considered disabled, and for what reasons. By “indigenous understanding” it was presumed that the main influence on understandings of disability would be traditionally African, or Lozi and Mbunda given the most common tribal heritages among the participants.

By describing the nature and context groups, it has been shown that eligibility in a group united around disability was not a good reflection of traditional understandings. The groups have been more highly influenced by recent concerns and contemporary contexts, such as foreign missionaries, local government offices, and indeed, this study. Instead of being long-established and straightforward, disability status in this context seemed to be evolving, flexible, contentious, and responsive to stimuli.

4.4.2 ‘The two-sided poverty coin’ and disability

The urban group and the rural group differed in structure and location. Despite this, the interrelated phenomena of material resources and a life of suffering as two sides of the same poverty coin was the main concern of both. The relationship of poverty and disability is one that has been studied in depth [24,25]. Due to the prominence of the issue of poverty in this co-construction, these findings are able to make important contributions to knowledge of disability and poverty in the global South.

4.4.2.1 Disability and poverty as a vicious circle

Most commonly, disability and poverty have been presented as a vicious circle [26], such that experiencing one increases the probability of experiencing the other. Indeed, many participants in this study framed their situation in a fashion that is similar to one half of the vicious circle:
that their disability contributed to their lack of material resources, which was the foundation of their lives of suffering. When speaking of things in a cyclical manner, participants did not draw upon a ‘disability-causes-poverty-causes-disability’ frame but instead spoke about how a lack of material resources made it difficult to generate or acquire additional material resources; in effect, that poverty-begets-poverty [27]. In the ‘revised vicious circle’ that was co-constructed in this study, impairment (or disability as a reflection of function) is almost absent. Instead, impaired function is only relevant in that it initiates the vicious circle.

4.4.2.2 Poverty as an integral part of disability

Not all participants spoke of their experience as one of cause-and-effect; many spoke of a lack of material resources and poverty as if it was integrally part of the experience of disability. Although the presentation of the relationship between disability and poverty as a mutually reinforcing cycle [26] is dominant in the literature, it is not universal. In a discussion of the common experiences of marginalization, isolation, deprivation and lack of access, Yeo notes the similarities between poverty and disability and states that “perhaps the relationship would be better described as interlocking circles” [28]. It seems that these participants are therefore not alone in seeing poverty and disability as fundamentally similar, rather than distinct but associated.

The results of this study point to a conceptualization different than Yeo’s interlocking circles [28]. Whereas interlocking circles implies that there can be poverty-without-disability and disability-without-poverty, the participants in this study did not speak in this manner. Instead, the participants spoke only of a disability/poverty in which everyone who was disabled was poor, and everyone who was poor was disabled. In effect, when speaking of poverty as integral to the experience of disability, the participants in this study spoke as if there was only one circle: that of disability/poverty.

4.4.2.3 The value of finding the poverty coin

The results of this study demonstrate how established conceptualizations of the relationship between disability and poverty can be helpful to understand the situation of a given context, but that sometimes these need to be modified to be robust. However useful this demonstration, the more remarkable finding of this study is the prominence of poverty in the accounts of persons
with disabilities. Although aspects of function and impairment were part of the participants’ conceptualization of their own situation as disabled, it was as if these considerations were less important and less interesting than the experience of poverty.

Poverty was more prominent in the accounts than impairment and function, but also more prominent than other possible considerations. One perspective on this is to compare the concerns of these participants to the CBR matrix [29] as a template of potential considerations. Of the five components of the CBR matrix, the participants’ concern was weighted very heavily towards the “livelihood” component. Furthermore, participants spoke of each of the elements of the livelihood component with regular reference to self-employment, waged employment, financial services, and social protection.

Meanwhile, the participants’ references to other components of the CBR matrix were generally subservient to livelihood considerations. An example of this is education. Participants spoke of limited education opportunities primarily in terms of a lack of resources, such that access to money was the solution to allow access to education. Concerns related to the health component of the CBR matrix were rarely brought forward by participants. When participants were asked questions related to the health component elements of disease prevention, medical care, and rehabilitation, the participants responded with general disinterest, even when acknowledging that these services were not available to them.

4.4.3 The “nature” of this study’s context

This research occurred in one urban site and one rural site of Western Zambia. Nonetheless, the context of the research is more complex than this declaration. The research also occurred as part of a co-construction with a researcher from a high-income country who arrived in the field with implicit and explicit connections to material resources. This study was not designed to ‘measure’ the impact of the co-construction relative to other influences upon the participants’ expressed concerns. Nonetheless, it is possible to reflect upon the ways in which the co-constructed context would be more or less influential.

When speaking of material resources, the participants often spoke about how the first author could make direct contributions to meet the participants’ needs. Despite the repeated requests, the first author refused to engage on these terms. These refusals were not because of an inability
to respond to the requests, but instead due to a different understanding of the role of the first author: he approached the field as a student researcher with the goal of generating knowledge. In effect, the participants’ assessments of the capacity of the first author to meet at least some of their requests was correct. This realization begs the hypothetical questions: how would the data generated be different if the researcher was not seen to have access to material resources? How would the data be different if the researcher had obvious access to other resources? Although it is not possible to know how the answers to the above questions, it is reasonable to suspect that there were practical reasons for participants to prioritize material resources in this co-construction.

On the other hand, there is also reason to believe that the co-construction is not the only reason for the prioritization of material resources. As shown in the descriptions of each group, the participants’ drive to organize themselves as groups was largely influenced by the search for material resources. With the collective consideration of this co-construction and the descriptions of these groups, it is suspected that the emphasis on poverty that was identified in this study could have been magnified by the co-construction. Meanwhile, it is also likely that poverty – understood as a lack of material resources and a life of suffering – could still be the participants’ main concern in other relational contexts.

4.4.4 Considerations for additional research

This study was developed as part of the movement to better understand the plurality of disability. The study was designed to be exploratory, with the attempt to minimize pre-conceived ideas about disability on the part of the researchers. This exploration showed that the participants’ main concern was poverty as an interrelation of material resources and suffering, a finding which raises deeper questions about how poverty relates to understandings about disability in this context. A concern with poverty could be consistent with any of the charity, medical, or social models of disability (among other possibilities), and could be an entry point to think about the relation of bodies, individuals, groups, identities, society, and more.

The participants in this study drew upon the negative aspects of life with a disability, making it apparent that their situation is one that could be improved. The knowledge generated in this study can be used to improve the situation of persons with disabilities in the global South by clearly identifying problems in a culturally-grounded manner, such that these can inform the
development of more robust solutions. This specific project is ongoing, and includes further engagement with the research participants to seek solutions. Since the main concern is poverty, the proposed solutions from this project will be focused upon that concern. Beyond this study, there remains an urgent need for additional solutions to address the myriad of factors related to poverty and disability.

4.4.5 Limitations

This study was consciously designed to focus more upon the experience of collectives as opposed to that of individuals. However, by so doing it was not possible to explore the experiences of persons with disabilities in Western Province who are not attached to a group. It has also meant that the analysis has focused upon the group level, investigating the commonalities within one or more groups, and contrasting the main differences between them. The analysis of these data has not included potentially important differences within the groups, such as that of gender, age, wealth, social status, or ‘disability type.’ Considering that the experiences of persons with disabilities are not homogenous [5], various sub-group and individual analyses could yield important insights.

4.5 Conclusion

This research described two very different groups united by the issue of disability in Western Zambia, each one having been influenced by its unique local context. The members of those groups who participated in this constructionist research expressed overwhelming concern with poverty, as expressed through the interrelated phenomena of a lack of material resources (i.e., money or things that could be exchanged for money) and a life of suffering. These findings contribute to the expanding literature on culturally- and contextually-grounded understandings of disability and create a platform for additional research.

4.6 References


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Chapter 5

Finding *help*: Exploring the accounts of persons with disabilities in Western Zambia regarding strategies to improve their situation

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Abstract

*Purpose:* This study aimed to explore strategies to improve the situation of persons with disabilities (PWDs) in the global South, through a co-constructed dialogue between a North American rehabilitation professional and two disability groups in Western Zambia. The research question was: how are strategies to improve the situation of PWDs framed within the accounts of these disability groups?

*Method:* Eighty-one disability group members were recruited for this constructionist qualitative study. Data were generated through semi-structured interviews and focus group discussions about life with a disability and ways to improve it. Data were analyzed thematically.

*Results:* Participants framed strategies to improve their situation as *help*: gifts or grants of material resources. *Help* is provided by those with the means to share, but influenced by the presentation of need by potential recipients. *Help* occurs in a relationship of expected compassion.

*Conclusions:* Currently, the formally-supported strategies to improve the situation of PWDs in the global South are influenced by the dominant worldview of the global North. *Help* is a radical departure from these existing strategies. Further consideration of *help* can be used to develop strategies that are contextually-grounded in the global South and inform potential improvements to existing or emerging strategies.
Finding help: Exploring the accounts of persons with disabilities in Western Zambia regarding strategies to improve their situation

5.1 Introduction

5.1.1 Disability: a global issue best addressed together with those who experience it

Disability is an important issue worldwide with over one billion individuals who are identified as disabled, the majority of these in the low- and middle-income countries of the global South [1]. Accordingly, it can be presumed that these large numbers of people have substantial unmet needs. This situation has led to calls for action to improve the situation of persons with disabilities (PWDs) in the global South through formally-supported strategies (i.e., those for which external actors like governments or non-governmental organizations provide support). But which strategies?

Critics have observed that many calls for action and their ensuing strategies are informed by a knowledge base that is exported uncritically from the global North and applied to the global South without consideration of its (in)appropriateness [2,3]. Dominant worldviews in the global North therefore have a direct bearing on the formally-supported strategies aimed at improving the situation of PWDs in the global South. A key point of this critique is that de-contextualized trends and orthodoxies dominate the landscape of possibilities, overshadowing or disregarding the voices of the actual people who live with disabilities in the global South.

Listening to the voices of PWDs in a particular context is consistent with the General Principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [4] and likely would be more effective at meeting people’s actual needs [5]. Given that the global South is not a singular and homogenous entity [6], it is reasonable to expect that efforts to listen to the voices of PWDs, let alone work in allyship [7] with them, ought to be contextually-grounded. Nonetheless, it is possible that lessons learned in one context can be transferred to another context, provided these are considered carefully and critically (e.g., Indigenous Project #24, “Discovering the beauty of our knowledge” by centralizing traditional knowledge before considering the potential of Western science to offer new insights [8]).
5.1.2 Purpose

The purpose of this study was to explore and develop strategies to improve the situation of PWDs in the global South, as informed by the voices of PWDs themselves. This study was contextually-grounded to a particular social dynamic and geographic location. The social dynamic was that of a North American rehabilitation professional in dialogue with two groups united around the issue of disability. The geographic location was two sites in Western Zambia, one urban, and one rural. The specific research question was: how are strategies to improve the situation of PWDs framed within the accounts of participating disability groups in Western Zambia?

5.2 Methods

5.2.1 Study design and context

This study was part of a larger project, the methods of which have been described in detail elsewhere [9]. The larger project was designed as qualitative constructionist research [10] with attention to participatory [11] and critical [12] concerns. The study was conducted in Zambia’s Western Province, an area with 900,000 residents, the majority of whom live in rural areas [13]. Western Province is a relatively undeveloped and distinct province in Zambia. Although the population now includes people from a variety of tribal backgrounds, the Lozi language (Silozi) and culture still predominate in Western Province.

5.2.2 Study team description and positionality

The principal investigator (PI) for this study was a PhD student researcher from Canada, supported by a supervision team of experienced academics from Canada and Zambia. The PI was a rehabilitation professional by background and had worked to develop disability and rehabilitation programming in other countries of the global South. He lived in Zambia for just over one year to conduct this research. Half of this time was spent in the capital of Lusaka to prepare the project with national-level Zambian partners; the remainder was spent on-site in Western Province. The PI is a White non-disabled male in his 30s who grew up in Canada with English as his first language. He was learning local languages over the course of the study and attained basic functional capacity in Silozi. Study activities were supported through the work of five paid research assistants from Western Province. All grew up in Western Zambia speaking
local languages as their mother tongues. All considered themselves non-disabled, were in their 20s, and were either post-secondary students or recent graduates. Three of the research assistants were women and two were men.

5.2.3 Participants

A two-stage recruitment process was used for this study. The first stage of recruitment was for groups united around the issue of disability; one in the provincial capital of Mongu, the other in a remote area of a rural district. Each of the groups was identified through contacts in Government of Zambia offices, and each was approached through its group’s leadership. After the groups’ leaders agreed to participate, the individual members of the groups were approached for their consent. Twenty-two (22) members of the urban group participated in the data generation activities, while 59 members of the rural group participated.

5.2.4 Data generation

Data was generated through focus group discussions followed by semi-structured interviews, followed by a second set of focus group discussions. The PI led all data generation activities. To allow participants to speak in the language of their choice, a research assistant translator, fluent in multiple local Zambian languages, performed real-time translation.

The first round of focus group discussions and the interviews were based upon a similar premise: open-ended questions about life with a disability and how it could be improved. Through these questions the participants were asked to describe their disabilities and their lives from their own perspectives. They were also asked about the strategies that did or could improve their situation. By the second round of focus group discussions the PI had come to know the participants and the area far better. For this second round he created a list of specific strategies that he had learned through the data generation activities and beyond, presenting each strategy during the focus group discussion and allowing participants to share their understandings and opinions of these strategies.

All data generation activities were audio-recorded and all speech was transcribed by the research assistants. Transcription was performed according to procedures that were described in a transcription guide drafted by the research team (See Appendix 1).
5.2.5 Data analysis

The analysis of these qualitative data was conducted by the PI with the guidance of the supervision team. Data analysis was guided by the principles of thematic analysis described by Braun and Clarke [14]. Specifically, the process began with a detailed reading of all transcripts. This reading helped to inductively develop the initial coding structure. Initial codes were reviewed for their pertinence to the research question, and then refined into themes. These themes were further developed through visual schematics, written documents, and discussion with the supervision team.

5.2.6 Ethical considerations

Research ethics approval was granted by the University of Toronto Research Ethics Board (Appendix 14), the University of Zambia Humanities and Social Sciences Research Ethics Committee (Appendix 15), and the Zambian Ministry of Health (Appendix 16). Practical ethical considerations included supporting travel costs when paid motorized transportation was available and providing a meal for focus group discussions or snacks for meetings. The identities of participating individuals and groups are described in general terms to allow readers to comprehend their situation while maintaining anonymity. Critical [12], post-colonial [3,15], and global health principles [16] were also used to inform ethical practices.

5.3 Results

The purpose of this study was to explore and develop strategies to improve the situation of PWDs in the global South, as informed by the voices of PWDs themselves, through a co-constructed dialogue with a North American rehabilitation professional. During data generation activities, the participants of this study framed strategies to improve their situation through a single theme: help (Silozi = kutusa). When speaking of help, the participants described the phenomenon according to a particular meaning, with specified ways of doing help, and according to a given rationale. The facets of help are represented visually in Figure 5.1, while each facet is described individually below.
5.3.1 The meaning of *help*

When referencing *help*, participants were generally speaking of gifts or grants of material resources (i.e., money and things that can be purchased with money), as captured by the following interaction:

*Interviewer*: When you say “to help those people who are suffering,” what do you mean?

*Participant*: I mean that if you can help us so that we can also help ourselves.

*I*: So when you say “so that you can help yourselves,” what do you mean by that?

*P*: Helping us really.

*I*: I still don’t understand.

*P*: Helping us, that if you find a little something, then you give us.

Woman with a physical impairment due to leprosy, rural group

In the case above, the participant implied that the “little something” should be a gift, without specifying the nature of that gift. Given that during the data generation activities the participants
spoke repeatedly about the lack of material resources as a fundamental problem of living with a disability, it follows that the suggestion refers to “a little something” of money or things that can be purchased with money.

In other cases, participants were less specific about the gift element of help, but were more explicit that help was money:

**Interviewer:** But I wonder what type of support would actually be helpful to make more people succeed. What do you think?

**Participant:** This time around, help is centered on money. There are some people who would want to buy some oxen, ploughs and other implements but they cannot because of lack of funds.

**P:** Certainly, yeah.

**I:** So our money, our livelihood, is centered on money, everything depends on money.

Man with physical impairments, rural group

In the quote directly above, the participant included a time marker in his account (“this time around”), possibly in referential comparison to another period when help might have been equally necessary but different in nature. In this case, money was mentioned as being necessary, even if the utility of this money was for conversion into other resources.

In some instances, participants spoke of help in terms of material items. One participant from the urban group referenced a supply of food, including beans and maize meal, as examples of “things which have come to help people.” Another participant from the urban group spoke of his lack of oxen for farming, such that he depended to provide these for him seeing as “there is a lot of help we need for us to survive.”

Although the descriptions of help may have seemed varied in the sense that they included money, money to buy resources, and the direct provision of the resources, these possibilities were presented in a fluid, practically interchangeable fashion. Due to this fluidity, the substance of help is best identified as material resources, an umbrella term to encapsulate money and things that can be purchased with that money.

With regards to the method in which material resources are transferred with help, participants spoke of help in ways that are similar to gifts or grants. Although this description involved the
PWDs acquiring material resources without payment, there was more nuance and detail with respect to the practice and expectations of help than it merely being a selfless and voluntary act on the part of the donor. These details are presented in terms of the practice of help and the rationale behind it.

5.3.2 Doing help: the who and the how

Participants spoke of patterned roles that helpers and recipients play in the process that is doing help. A participant from the rural group, an older man with a physical disability described the important role of the helper in initiating help:

It’s that [helper] who should choose that ‘I can help this one but I will not help this one; I am helping maybe this one because of maybe the way he is and I will not help this one.’ But it is chosen by the one that is who is who supposed to give, not the person who supposed to receive.

With the prominence of help as an intervention strategy to improve the situation of PWDs, the identification of helpers and recipients was crucial to understanding disability. According to that participant, persons with disabilities were those “who need to be helped,” although he mentioned that the elderly also shared this characteristic. Connecting these considerations, it seemed as if a person needed to be endorsed by a helper to be considered disabled. This possibility was reviewed with the participant:

*Interviewer:* So that means that its only people who have things to give that can decide ‘this one is disabled and this one is elderly.’

*Participant:* The one who gives is the one who sees.

Participants repeatedly emphasized the importance of ‘those who have things to give.’ In some instances, these people would be ‘well-wishers’: individual neighbours and friends who would help with gifts of food and supplies. As stated by a woman from the rural group with physical disabilities due to leprosy, “I get some help from well-wishers…Someone has helped me with some fish maybe someone will also help me with some mealie-meal so that I can prepare some food.”

In other instances, helpers were institutions, such as religious, civil-society, or governmental entities. Within these interactions, participants spoke of the power of the helpers to specify the recipients, nature, and quantity of help to be provided. Nonetheless, the potential recipients had a
role to play in facilitating the provision of help. When speaking of the process that the rural
group could follow to improve their situation, the commonly-identified informal group leader
cited the key role of institutional helpers: “We ask the money from the government…we tell
them that ‘we want to do this, we want to do this’ and then when they feel mercy [makeke] for
us, they can give us, then from there, we can change other things.”

Beyond discussing help, the participants engaged in the process of doing help, as potential
recipients, within the interactional context in which the data for this study were generated. The
PI was a person of privilege relative to the participants, and was accordingly approached by
participants with numerous requests for help. One direct request came from a participant from
the urban group who matter-of-factly stated during an individual interview that he joined the
study so that the PI would build him a house. Another direct request was from an elderly
participant in the rural group who declared to the PI during a focus group discussion that, “You
will help us!”

Although a few requests for help were direct, many other potential requests were ambiguous,
couched in humour or subtlety. Among the likely requests was a proposal from a participant in
the urban group during a focus group discussion that the PI “can be my pen pal (laughs) and help
me.” During an individual interview another participant from the urban group outlined a series of
expenses that he was facing before stating to the PI, “If I was to find a donor who can help me
with those things I can feel very happy.”

In discussing and doing help during this study, participants emphasized their roles as recipients.
Often, this role was reinforced through its connection with impairment or disability status. Even
in cases where persons with disabilities showed initiative or created value, these cases were
presented as impossible without external help. This phenomenon was exemplified through an
exchange with a man from the rural group with a physical disability in a discussion about a
defunct craft workshop:

Participant: [Persons with disabilities] were happy with [the workshop]. Because it
used to help people who had disability. So that they can find ways and means and
how they can help themselves. So that they should not always be looking forward
to the government to be helping them every day.

Interviewer: So the people who were trained in that workshop, how many are still
doing those jobs?
P: The people, they are still around, yes, but they are not doing that job because they do not have the resources. Sometimes, to do those traditional trades, you need to go in the bush and get those roots which are used to make those things. Now if someone is disabled, how can you go in the bush? How are you going to carry those things?

I: Ok, so in that case then I am confused. Because a moment ago, you said people were happy with the handicraft. But now you are telling me that it cannot help a person with a disability?

P: No! What I am talking about are the resources like the trees, the planes, the saw, and other things that are needed for one to use. All those things, you need money for you to purchase those things. That’s what I am saying: everything depends on money. Because [the foreign missionaries] used to work there, what used to happen was, [the missionaries] would buy those [supplies and equipment] and bring to those people with disabilities to say ‘Can you make this? Can you do this?’

In other discussions, the PI asked about the possibility of persons with disabilities generating the resources themselves through collections or accumulating them through small tasks and savings. According to participants, this was not the way that things worked: even when persons with disabilities helped themselves, the process necessarily involved the infusion of resources from an external helper.

Although exceptional, there were situations where a person with a disability could be a helper instead of a recipient. One was a reference from a parent with a disability in the urban group about helping his children. Other references were from the leaders of each of the groups. The urban group had a formally-recognized chair, whereas the rural group had one member who was informally considered to be the main leader. Both of these leaders appeared to be of a higher economic status than other members, with the larger and nicer houses of these leaders serving as meeting places for the groups. In both cases the leaders spoke about help that they offered to other members in the group, even though these contributions were small as compared to the help they hoped to secure for the group. As a specific example, the leader of the rural group owned a small shop, from which we would occasionally take salt, giving it to others and suggesting that they “go and put in [their] relish.” Regardless, as presented above, he saw the way forward for persons with disabilities to involve a combination of collective organizing and help from the government: “Yeah, things that can help change is if we fight we make our own groups, just us here. And then we ask the money from the government.”
5.3.3 The reason behind help: expected compassion

Participants rationalized the practice of help through a relationship of expected compassion between people of different economic and ability statuses. Specifically, participants spoke of help as being motivated by a feeling of makeke on the part of the helpers. The research assistants initially translated the Silozi makeke into the English words ‘pity’ and ‘mercy,’ but in the instances where participants spoke of makeke they implied more of a sense of warmth and caring than is meant by pity or mercy. A dictionary translation of makeke into the English word ‘compassion’ seems a better fit to the participants’ descriptions [17].

Some examples of this phenomenon emerged during a focus group discussion with the urban group, expressed here as per the original, real-time translation of makeke. One woman with a physical disability spoke of her difficulties finding food, but that “If a person does not have food, others feel pity for her then they give her.” A man with a physical disability spoke about how he was allowed to ride a bus to the capital without paying the fare. When the PI asked the man “Do you think [the driver] did that because he had to, or because he wanted to?” the reply was “He helped me because…out of pity.”

With compassion as a motivating sentiment and helpers able to choose whom to help and how, it might seem that help was directed solely by the internal compass of those with the resources to help. On the contrary, participants spoke of an expectation to receive help, and expressed disappointment when they felt that a potential helper had the capacity to help but did not do so in the face of legitimate need. According to a participant in the urban group, “I have relatives who are really working. But there is no help that I receive from them.” Another participant from the urban group spoke of the way in which acquaintances did not share with her family since they “do not like me because I have nothing to give them,” forcing her to beg for food from others.

The expectation of help was not limited to individuals; it also applied to institutions. A participant from the rural group focused his expectations on the government instead of neighbours:

Even when you would sit without food or you die without food you can’t go there because if you go there you know that they will not give you food. Or if you go there to say I don’t have blankets to cover myself. We have maybe 10 years without finding blankets to use in this [community].
Another participant, this one from the urban group, spoke of her expectations that a non-governmental organization would provide help, during a focus group discussion: “One time I went there; I did not have maize flour. I went there to ask if they can help me, but they just gave me 2 lumps of nshima (the maize-based staple food) and some cooked beans.” The other participants broke into a disappointed laughter upon hearing of this insufficient form of help.

Since nearly all of the discussions about help were framed from the position of potential recipients, there are few explanations of the motivating factors from the perspective of a potential helper. One exception to this was the man considered to be the leader of the rural group, who, as described above, owned a small shop. He spoke of his practice of helping others in compassionate terms, stating “when I have something, then I give.” And yet in describing the way he selects the recipients, there was an element of calculated distribution: “It is at times, like this time you remember giving this one; this time you give someone else.”

Participants spoke of help as being motivated by compassion, yet it seems that compassion is not completely voluntary. Instead, compassion is expected, by the potential recipients at the very least. Taken together, potential helpers and potential recipients within a given community seem to be bound together through a relation of expected compassion that is manifested through the practice of help.

5.3.4 Summary of results

Within the accounts of participants, help was framed as a predominant strategy to improve the situation of PWDs. Participants spoke about help as essentially a gift or grant of material resources. Help was enacted by potential helpers and recipients playing specific roles. Participants spoke of these roles in reference to relationships outside of the research, but also performed the role of potential recipient during the data generation process. Participants spoke of a relationship of expected compassion as the motivating force behind help.
5.4 Discussion

5.4.1 Help as a strategy to improve the situation of persons with disabilities

The strategy co-constructed in this research, help, is fundamentally socio-economic. Help is economic in that it is a mechanism to distribute scarce resources. Help is social in that it is built upon human relations and expectations of compassion. The way in which help was co-constructed in this research is similar to the conception of gifts as elaborated by Mauss [18] and the understanding of the social nature of “African economies” as described by Maranz [19]. Each of these ideas is useful to better understand help.

5.4.2 Similarities between help and Mauss’ conception of gifts

Marcel Mauss authored a seminal text on gift giving that proposed that the practice can be simultaneously self-interested and disinterested [18]. Mauss was a French sociologist active in the first half of 20th century. His study of gift giving was a review of ethnographic research from Indigenous tribes around the Pacific Ocean and ancient legal texts [18]. The prime value of “Mauss’ system of The Gift” [20] is that it stands in relief to the Eurocentric modernist conception that self-interested economic activities are distinct from disinterested (or selfless) charitable activities. The argument proposed by Mauss is that the distinction between economy and charity is recent and self-imposed to society’s collective detriment. To this effect, Mauss saw the modern conception of gifts as purely charitable acts as being flawed for its attempt to eliminate the possibility of reciprocity [21]. Other authors have built upon Mauss’ foundation by discussing gifts in the contemporary global North, expanding the conception beyond material items to include abstract aspects such as advice and volunteer labour [22,23]. Specific to international relations, authors have referred to Mauss in order to better understand development practices [24] and development assistance [20].

In discussing their situation and ways to improve it, participants in this study spoke frequently about help, but generally described this in terms of who should give what to whom. This conception, and the emphasis upon material resources, is similar to Mauss’ description of gifts [18], while being dissimilar to abstract aspects of gifts. Moreover, the participants’ accounts included references to particular people in particular roles relative to one another, and of
relations that can grow and strengthen through the exchange, which is also similar to Mauss’ conception of gift giving.

It is tempting to identify the consistency between the accounts of these participants and Mauss’ original descriptions as both emerging in traditional societies (if we consider contemporary Western Zambia to be culturally traditional), but this explanation ignores the extent to which participants spoke of money, the central medium of transaction in modern economies. An alternative to this explanation is more likely. The emphasis on material resources could be a direct result of the context of this research: the most prominent concern of participants was poverty [9], and the PI could be seen as a potential source of these resources. The combination of these two elements likely influenced the participants’ focus on material gifts as opposed to alternatives.

5.4.3 Similarities between help and Maranz’ description of “African economies”

Unlike the seminal academic contribution of Mauss, David Maranz has provided a practical guide to help Africans and Westerners navigate the day-to-day challenges of differing understandings of societies and economies [19]. Maranz is an American anthropologist and Christian missionary who lived in various locations in West Africa. Maranz readily admitted that one should not homogenize either Africa nor The West (i.e., the global North), yet sought to present characteristics that could be understood as generally accurate for both Africans and Westerners. Although not explicitly influenced by Mauss, Maranz’ presentation of the generalities of “African economies” is similar to Mauss’ conception of gifts in that each is designed to enhance collective solidarity. Maranz’ overt connection of “socio” to “economic” is also similar to help.

Since Maranz’ contribution was grounded in Africa, it is likely to be even more relevant to this study’s context in Western Zambia. Moreover, Maranz presented two ideas that are useful in thinking about help: 1) asymmetry, and 2) microsolutions.

According to Maranz, many of the socio-economic practices common in Africa have developed in order to facilitate collective needs in situations of asymmetrical wealth. Through practices that are collectively understood in many African societies, “patrons” provide material support in
exchange for respect, reverence, and the possibility of future reciprocity. Participants in this research clearly identified themselves as potential recipients in need of support from helpers. Participants spoke explicitly of the rationale motivating helpers as compassion, and indirectly about expectations, but is it possible that there is more nuance to this rationale than what can be derived from the data? Compassion is consistent with a sense of collective concern and solidarity, suggesting that Maranz’ explanations could inform the concept of help. Furthermore, some participants included their inability to reciprocate as part of the reason that they have not yet received help. Taken together, the co-construction of help seems consistent to the principle of asymmetrical exchange for communal well-being as described by Maranz [19].

In addition, Maranz proposed that many aspects of life in Africa are socio-economic microsolutions. In describing microsolutions, Maranz claimed that these are ways to immediately address problems on a small scale without challenging larger structures in an environment with significant uncertainty [19]. The disadvantage that PWDs in Western Zambia face is likely longstanding and probably maintained through systematic society-level factors. Despite these characteristics, the participants in this study identified the microsolution of help as a preferred strategy to counter disadvantage and improve their situation. The consistency of help with Maranz’ descriptions of “African economies” allows for a more comprehensive understanding of socio-economic norms that could underpin participants’ suggestions of help as a strategy to improve the situation of PWDs.

5.4.4 The relevance of disability as a problem to be addressed through help

Since the main finding of this research was help, a socio-economic solution, it is possible to think that disability was irrelevant or absent. This was not the case. First of all, for the participants, the primary concern in their lives was poverty, a concern that they saw as inherent to the experience of disability [9]. According to this frame, disability and poverty were almost inseparable. Furthermore, the participants made links between their status as PWDs and their eligibility to receive help from others.

Although this study was conducted exclusively with people who experience disability, it is completely possible that the (non-disabled) neighbours of the participants were similarly poor in terms of earnings and wealth, and also relied on help for acquiring some of their resources. From
5.4.5 Using help to inform the development of strategies

*Help* is markedly different than the prominent formally-supported strategies to improve the situation of PWDs in the global South. Prominent strategies in the global South have been influenced by the dominant worldviews of the global North; initially charitable and medical conceptions of disability during the colonial era [25, 26] and then more recently the social model of disability [2,3]. These worldviews have informed the development and export of formally-supported strategies such as rehabilitation [26], inclusive education [27], and social welfare [28], among others.

At first glance, *help* might appear to be a strategy responding to a charitable conception of disability, but it diverges from this conception in two important ways. First, charitable conceptions of disability are typically understood to be imposed upon PWDs by others [25], whereas *help* responds to a conception of disability to which PWDs are actively contributing. Second, the dominant understanding of charity is that the recipient is passive and disempowered, whereas *help* seems to reflect fundamentally different socio-economic principles whereby people can engage and exchange respectfully across various levels of wealth status.

The finding that *help* was the single theme framed by participants to improve their situation calls into question the alignment of the predominant formally-supported strategies with the worldview and priorities of PWDs in Western Zambia. The main value of *help* as a strategy to improve the situation of PWDs is in its radical departure from the status quo. *Help* can therefore be used to inform further action in the context of the study, as a set of principles to create new strategies, and as a base of comparison to inform the critique of existing or emerging strategies.

5.4.5.1 Using help to inform further action in this context

This study was developed using participatory research principles whereby a project is intended to generate knowledge and inform practical action [11]. With *help* having been framed as the
strategy to improve the situation of the participants, a new challenge has been created: how can the PI effectively operationalize his involvement in help as the practical action resulting from the project? Clues with respect to the approach could be found within the data; specifically, from the example set by the group leaders. Leaders provided some of their own resources to benefit others in the groups, but their primary role has been to seek resources from outside sources. Bruun [29] discussed the provision of small amounts of resources to collaborators as a researcher in Zambia, presenting both challenges and benefits of this practice. Meanwhile, securing resources from other parties is a role that the PI could be well-placed to fill. Considering the value of the PI to maintain the research relationship with the participants, this ongoing involvement through help can be seen as consistent with Mauss’ [18] description of an activity that is simultaneously self-interested and disinterested, or Maranz’ [19] description of asymmetrical reciprocity. An ongoing research relationship of reciprocal benefit challenges the frames in which research ethics are often conceived [e.g., 30]. Yet even in such a partnership of mutual benefit and vulnerability, the structural forces that allow some people to be researchers while others are researched will always carry a threat of exploitative power dynamics that must constantly be recognized and managed [31].

5.4.5.2 Analyzing components of help to inform new strategies

The characteristics of help could be useful to guide the development of new strategies. One key characteristic of help is that it is based upon a relationship. The relationality of help might seem to conflict with the nature of institutions, yet help shares similarities with formally-supported programs such as peer-support or peer-mentoring. Help diverges from these peer-based programs through its foundation on wealth differences between participants rather than commonalities and its exchange of material resources rather than advice. It is therefore difficult to see how help could be “scaled-up,” yet these could be considerations for practice innovations and future research.

Although participants spoke positively about help in this research, there are foreseeable weaknesses with this strategy. The loss of a helper entails a loss of material support, leaving this strategy vulnerable to the presence, and continued wealth, of the patrons. Such a strategy could also perpetuate discrimination where social minorities are not chosen to be recipients of help. Conversely, commitments to redressing inequalities on the part of helpers could lead to the
creation of different forms of help where resource flow is more reciprocal. Help, as framed here, is unconcerned with productivity, and promotes interdependence over independence. These qualities are not inherently positive or negative, but could be more or less beneficial depending upon the circumstance.

5.4.5.3 Constructive critique of established or emerging strategies

In addition to informing the development of new strategies to improve the situation of PWDs, help can also be useful as a base of comparison for formally-supported strategies that are currently prominent in the global South, or at very least in the process of emerging. Through this comparison, it is possible to identify the synergies and the incongruences of these strategies with the accounts of participants.

One predominant strategy to improve the situation of PWDs is rehabilitation. The field of rehabilitation is one that can be understood in multiple different ways (including community-based rehabilitation [32]), but is nonetheless largely descended from Western biomedicine [26]. Rehabilitation activities often aim to improve or increase function, which could admittedly lead to a reduction in poverty through the mechanism of increased productivity. Participants in this study did refer to reduced function, but typically to justify the need for help, not as a problem requiring a solution in-and-of itself. Although rehabilitation interventions could provide positive outcomes for at least some of the participants in this research, they seem to differ markedly from the way that participants frame a strategy to improve the situation of PWDs.

An additional formally-supported strategy to improve the situation of PWDs is scaling-up in Zambia towards nationwide coverage: the Social Cash Transfer Scheme (SCTS) [33]. Zambia does have a history of social welfare support through the Public Welfare Assistance Scheme, but the SCTS is a significant move towards widespread, comprehensive coverage [33]. The SCTS is similar to help in that it is a direct grant of money; but different for its monthly distribution and its depersonalized nature. This government-supported welfare entitlement program could lead to important improvements in the standard of living for the participants in this study and many other PWDs in Zambia, yet a comparison to the co-construction of help reveals some weaknesses and vulnerabilities of this program. As Hansen and Sait [34] identified through their anthropological research in South Africa, a depersonalized system can be unresponsive, as community members are confused and angry that the system does not meet their needs.
Furthermore, a system of government-issued grants could undermine the culturally-supported and community-minded system of help. This undermining could occur if potential helpers begin to abandon the practice due to the government’s involvement. Considering the significant experience of poverty of the participants, the SCTS is undoubtedly a positive strategy to improve the situation of PWDs. In its practice, however, there could be frustration for PWDs who are confused that the system is not amenable to negotiation in situations of greater need. In addition, a discontinuation of the SCTS could be very negative for beneficiaries who would lose direct state support, and potentially be without help as well if potential helpers no longer give.

5.5 Conclusion

Participants from two groups united by disability in Western Zambia framed strategies to improve their situation as help. Help is understood to be a gift or grant of material resources, shared by a helper with sufficient means to do so and an awareness of a recipient’s need, and is provided on the basis of an expectation of compassion.

Help is different from formally-supported strategies to improve the situation of PWDs in the global South due to its relational nature, and its refocus from improving individual function toward a direct focus on poverty alleviation. For this project, help could be a mechanism to build relationships and make possible further research-action collaboration. More generally, as a departure from the global North worldview, the principles underlying help could be used to inform strategies appropriate for numerous locations in the global South. Finally, help could be used as a base of comparison from which to consider, critique and improve the established strategies to improve the situation of PWDs.

5.6 References


Chapter 6

Unanticipated productivity: using reflexivity to reveal latent assumptions and ideologies in postcolonial disability research

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Abstract

All research involves assumptions and ideologies, many of which go unidentified. Guided by the critical social science perspective described by Eakin et al. (1996), I reflexively reviewed experiences of disjuncture that occurred as I conducted disability research from a postcolonial perspective in Western Zambia. By systematically unpacking elements of the disjunctions, I was able to identify an unconscious assumption I held; that research participant productivity was the optimal mechanism to improve their situation. Through additional analyses of prior experiences and the interpersonal, institutional, and societal contexts to which I have been exposed, I further identified possible ideologies that might underlie my assumption. These ideologies included: 1) an experientially-derived belief in the untapped productivity of disadvantaged peoples, and 2) the ideational regime of productivism. By more clearly seeing my values with respect to productivity, I was able to propose alternative understandings of the concept, as they might be understood from the perspective of the participants. Having identified assumptions and ideologies of productivism in my own work by conducting a reflexive analysis, I call on other researchers engaged in postcolonial and disability research to engage in reflexivity.
6 Unanticipated productivity: using reflexivity to reveal latent assumptions and ideologies in postcolonial disability research

6.1 Introduction

In my doctoral dissertation research about life with a disability in Western Zambia, the participants spoke frequently about their need for help: gifts or grants of material resources from people who possess or have access to such resources (Cleaver et al., 2016c). Although the proposed helpers were often other individuals, the participants also regularly identified me as a potential helper in ways that ranged from subtle to direct. When they spoke in this manner, I understood that the participants were requesting material resources from me. These frequent requests occurred despite my having designed the study to pre-empt such possibilities, instead wishing to focus the attention of the dialogue elsewhere.

I experienced emotional reactions to the requests while in the field, responding with impatience and annoyance. In practice, I tried to influence the dynamics of the data generation to make such discussions less likely, quelling the requests for help in the form of material resources as they arose. I also avoided interactions in the community that were in my view unnecessary for my data generation when I thought that these interactions would lead to requests. The sense of discomfort lasted into the data analysis process. These data, with their constant references to help and material resources, somehow felt wrong, making them nearly impossible to approach analytically, since flawed data could only lead to flawed conclusions.

With temporal and spatial distance from the research field and new sources of insight (e.g., Maranz, 2001) regarding the ways that my participants could have understood the social economy, my discomfort gave way to intellectual inquisition. Why did I respond so strongly?

According to some perspectives, my reactions seemed reasonable and logical: given my position as an outsider of apparent privilege conducting global health research in communities of significant poverty, there was reason to pre-empt and correct misunderstandings about my intended involvement in the communities. In order to pre-empt these types of understandings, the recruitment and consent process involved multiple steps, including a personal discussion with each individual participant (Cleaver et al., 2016c). According to other perspectives, my devotion
to moving the dialogue in different directions might have surpassed reason. The taxing emotional responses that I experienced and inability to engage in early analysis could have been seen as excessive and problematic.

From the perspective offered by hindsight, I consider the anecdotes above to be embodied evidence of “disjunctures,” a term used by Mandel (2003) to describe a disconnect “between my expectations and experiences in carrying out… fieldwork” (p198). Similar to other doctoral researchers from the global North conducting research in the global South who had experienced disjunctures (Mandel, 2003; Sultana, 2007; Billo and Hiemstra, 2013), I looked back into my own research process using reflexivity.

The purpose of this paper is therefore to use researcher reflexivity as a strategy to better understand the disjunctures that I experienced, related to talk of help and material resources, in this research about disability in a postcolonial dynamic.

In this paper, I offer an overview of the study in which I experienced disjuncture in order to allow the reader a fuller understanding of the approach that I took to data generation and analysis. I then present a critical social science perspective (CSSP) (Eakin et al., 1996), which I use as a guide for the reflexive analysis. This analysis allows me to identify assumptions and ideologies that might have unconsciously informed my research, and in turn provides an invitation for me to see identify alternatives to my own initial ways of thinking. The identification of these assumptions and ideologies has implications for my own research, but also allows me to look differently at the ways in which others have studied disability in nearby, culturally-similar South Africa.

6.2 Overview of the study in which I experienced disjuncture

The fieldwork and analysis experience upon which I am basing this manuscript occurred in the context of a doctoral dissertation research project to explore understandings of disability and strategies to improve the situation of persons with disabilities in Western Zambia. I developed the research using a qualitative constructionist methodology (Silverman, 2006). As part of an effort to ground the project in social justice and emancipatory principles (Campbell, 2014), the study was further guided by a critical social science perspective (Eakin et al., 1996) and participatory research elements (Herr and Anderson, 2005). My interest in social justice and
emancipation developed from prior professional experiences, some of which I describe as part of the reflexive analysis below. These experiences steered me most markedly toward using a participatory approach in this research, but the experiences also informed foundational beliefs that undermined my capacity to follow a key element of that approach. For me, a participatory approach entailed the celebration of the participants’ initiative and an attempt to pursue collaboration between the researcher and the participants. In designing a study with a participatory approach, I took it for granted that I could find, or otherwise create, an environment in which initiative was celebrated and collaboration was desirable.

The dissertation research project was developed in consultation with national-level Zambian disability self-advocates who suggested that I work in Western Province. The national-level advocates connected me with provincial-level advocates who in turn informed me of the disability groups of which they were aware. Through the provincial-level advocates, I met the leaders of one disability group in the provincial capital of Mongu and another in a rural area of the province. The leaders of the two groups agreed to allow me to approach individual members to seek their consent. Ultimately, there were 81 individual participants from the two groups. The individual participants were primarily persons with disabilities themselves, but also included supportive family members.

The research data for this project were generated through focus group discussions and interviews. I led all data generation activities with the support of a staff of five paid research assistants who were born and raised in Western Zambia. The data generation fieldwork lasted a period of six months in 2014. During this time, I strived to develop contextually-appropriate participatory research relationships with the participating groups and their members in order to create a fertile dynamic for knowledge production and practical action. After the completion of the fieldwork, I conducted the thematic data analysis using methods described by Braun and Clark (2006) with the support of my dissertation advisory committee. The findings of these studies are published elsewhere (Cleaver et al., 2016b; Cleaver et al., 2016a).

6.3 A critical social science perspective (CSSP): a guide to reflexive analysis

This reflexive analysis is guided by the considerations of a critical social science perspective (CSSP) (Eakin et al., 1996). A CSSP identifies several key features of interest: assumptions and
ideology; the influence of overt, subtle, and covert forms of power; contradiction; and the
dialectic between structure and agency. For this reflexive analysis, the features of contradiction,
and assumptions and ideology are particularly useful. In a sense, the disjunctures that I
experienced were reflections of contradictions between my approach to the research and the
results that I was able to produce once I had the insight to understand the data differently. Using
a CSSP, I was challenged to use my awareness of this contradiction to adopt “a reflexive posture
towards research” and shine a light on “the basic assumptions and ideologies underlying the way
research problems and methodology are conceived [and] the dialectical relationship between the
formal and informal structures of society (institutions, social norms) and individual or collective
human action” (p 158). Effectively, the expectations that I had for the research were made visible
through the embodied experiences of disjuncture. In the language of the CSSP, these now-visible
expectations were assumptions:

All parts of the research process are based on assumptions, or taken-for-granted 'truths'.
Assumptions themselves reflect an underlying ideology, that is, a set of beliefs about social
reality as well as the customs, practices and behaviours which consciously or unconsciously
embody this vision of reality. (Eakin et al., 1996:158)

Despite my awareness that I had assumptions, I did not know what they were or what might lie
behind them. The reflexive posture encouraged by the CSSP begins with self-analysis: a review
of embodied experiences of research conduct (Billo and Hiemstra, 2013) in order to use these as
a platform for additional considerations. I reviewed, and built upon, my experiences to answer
two specific analytic questions: what assumptions did I take into this research? What ideologies
underlay those assumptions? Although I led all analytic activities, the process was facilitated
through dialogue with the members of my PhD supervisory committee.

6.4 Unpacking disjunctures to find assumptions

By reflexively analyzing the disjunctures experienced through the requests for help as material
resources, I was able to identify a specific collection of inter-related component characteristics
for which I was expecting the research to unfold in a certain manner. I describe each of these
characteristics individually, beginning with those that I explicitly pursued as part of my approach
to participatory research. I use these explicit concerns to identify other characteristics, and follow
the individual characteristics with a presentation of the ways in which these interconnect.
6.4.1 Initiative

This characteristic was one that I explicitly designed the study to find, particularly through the ways that the participants took initiative to improve their situation. Consistent to this, I understood initiative to be the quality of creating and implementing strategies as potential solutions to important problems.

During the fieldwork phase of the research, it was my impression that there were few examples of the participants taking initiative. My lack of detecting initiative, combined with the participants’ requests for help in terms of material resources initially made me frustrated. This combination made me believe that I was unable to find the initiative that the participants wielded, or alternatively, that the participants were just not wielding initiative. Either possibility distressed me: data generation that failed to detect initiative that was present was a failure of mine. Conversely, an absence of initiative on the part of the participants was a failure of theirs.

6.4.2 Collaboration

In parallel to having designed the study to identify initiative, I also designed it to encourage opportunities for me to collaborate with at least some of the participants as part of a general action-orientation. My impression of collaboration was that it would involve transparent communication about priorities and goals between the participants and me. My hope was that through transparent communication leading to priorities and goals, we could develop mutually agreeable tactics and pursue these through our respective actions. The consistency of communication and action was important; an alignment of word and action would be a sort of validation of the transparency of the communication. Furthermore, consistent communication and action would help build the trust that would be the foundation of a collaborative relationship. Through the collaboration, at least some participants and I would collectively be productive and make contributions (see below) through the knowledge generated in the research and some related practical activities. The practical activities would likely be realized through the dissemination of knowledge products that were targeted at (mostly local) influential audiences; a tidy synergy between the tasks required in a PhD and those that are useful to participating persons with disabilities.
I was ultimately able to engage in some collaboration during my dissertation fieldwork, but it was more elusive than foreseen, and occurred on terms that seemed somewhat problematic. During the early phases of fieldwork with the participants, there were very few who seemed to relate to my intention to collaborate. A more common understanding of my role that was communicated to me by the participants (more or less explicitly depending upon the interaction) was that it was my role to provide material resources to the participants. This understanding of my role was antithetical to my intention, and therefore a disjuncture between my expectation and actual experience. Identification of collaboration as a component characteristic of my experience of disjuncture is another piece of the puzzle. Identifying collaboration also allowed me to see contribution and productivity as potentially related characteristics of interest.

6.4.3 Contribution

Unlike initiative and collaboration, I had not explicitly declared my interest in contributions as part of the study design. Instead, I expected contributions to flow out of initiative and collaboration, with individuals and collectives contributing in useful and fulfilling ways. The Oxford Dictionary online (2016) defines contribution as “the part played…in bringing about a result or helping something to advance.” Taking this definition and applying it to the situation I was trying to create through the study, we might understand contributions as instances of people devoting effort towards the possibility of a valued outcome. In this sense, I thought that it would be rewarding and valuable for the participants to be able to contribute to their own well-being and that of other persons with disabilities. Contributions would therefore have a component of self-realization in the doing and a component of valued outcome after the doing was done. Furthermore, through the process of contributing, they would be able to shape the outputs to be those that were meaningful. Therefore, contribution simultaneously links input and output, while linking process and potential outcome, such that all are more appreciated and of higher quality.

In the actual experience of the fieldwork, I was able to perceive few examples of the participants contributing. If we think of contributions as doing things, what I saw instead was the participants asking for things. According to the approach that I took to the research, doing and asking were mutually exclusive activities in opposition to one another. In trying to create an environment to foster doing, the constant presence and prominence of asking left me disappointed. My
presumption here was that I was either unable to find the contributions that were happening or unable to facilitate opportunities for the participants to contribute.

6.4.4 Productivity

The quest for *productivity* was somehow everywhere in the design of my work, while I remained oblivious to its presence. Unlike initiative and collaboration, which I sought explicitly, and contribution, which was implicit, productivity was only made visible by its apparent absence. I first noted productivity when I noticed that I was viewing the participants as *unproductive*.

Once I recognized that I had an interest in productivity, it was easy to find. The rationale for me to identify initiative was to facilitate the sharing of techniques between some initiators with disabilities and others such that it would help the others to become similarly productive. I had hoped that participants would be able to collaborate in the research such that they would be more productive in that process than they could be if acting alone. I foresaw that disability might be conceptualized in terms of scarcity. These problems of scarcity could therefore be addressed by increasing the capacity of the participants to *produce* more things.

6.4.5 Connecting the dots to find the assumption

The characteristics of initiative, collaboration, contribution, and productivity that I have described as expectations that I took into this study can be seen to be interdependent. These characteristics could be seen as linked together in a chain that ultimately results in more *valuable products* that could be used to counter scarcity. In Figure 6.1, I present a visual representation of the characteristics I have identified in this reflexive analysis. This visual representation shows how the characteristics could be interdependently related.
Upon conducting the reflexive analysis, I noticed the extent to which I focused on productivity, approaching it almost as if it was an end rather than a means to achieve some other ends. In designing this research, I did envision some potential valuable products, such as reports to decision-makers that identified gaps in services for persons with disabilities. The potential valuable products that I had foreseen (reports) were different from the valuable products identified by participants (material resources). Nonetheless, in reflexively analyzing the disjunctures that I experienced, it became apparent that it was not the talk of material resources per se that I found to conflict with my assumptions, but instead the perception that the participants acquire material resources through a pathway that I did not consider to be productive. Through my strong reaction to what I considered to be a lack of productivity, as identified through its components, I began to see the extent to which I assumed the value of productivity by the disadvantaged of the global South, including the participants in my dissertation research.

6.5 Identifying ideology

By reflexively following the disjunctures, I identified the way in which I unknowingly brought the assumption of productivity into the study design. According to Eakin et al. (1996), “assumptions…are often implicit, rendered invisible because they are perceived as self-evident truths rather than as socially derived conventions” (p. 158). In order to identify the possible conventions and beliefs, the ideologies, that might underlie my assumption, I reviewed previous professional experience preceding the dissertation and the interpersonal, institutional, and societal contexts to which I have been exposed.
6.5.1 Prior professional experiences

While working as a physiotherapist in other locations in the global South, primarily through non-governmental organizations, prior to beginning my doctorate, I was regularly exposed to a donor-driven perspective of global health, international development, and international relations. This manifested itself through dynamics in which the disadvantaged of the global South depended upon donors for resources, sometimes even for basic needs. Importantly, unlike governmental programming (in principle, at very least), donor-driven programs generally did not have concrete accountability mechanisms to the population that they served.

I found two major issues with this donor-driven arrangement. First, it meant that the “beneficiaries” of the services lost some control through donor-driven agendas. I personally encountered these issues through my own work, although there are critiques that are much more broad and thorough than my own (see McGoey, 2015). A second issue with donor-driven agendas is that of scalability (Liu et al., 2011). Since the reach of donor-driven programming is bounded by the amount of resources that the donors are willing or able to share, the boundaries of service are often restrained. Recognizing that in the global South there are indeed many people who relied upon donor-driven programs with a concomitant loss of control and a lack of scalability, it certainly seemed an alluring alternative that those in need could be productive to improve their situation.

Moreover, I believed that the value of productivity could be amplified if pursued using appropriate technology, “technologies that are easily and economically used from readily available resources by local communities in the developing world” (Pearce et al., 2012). Using such technologies, I thought, individuals and communities in the global South could have the option of greater independence, possibly even solving other societal problems such as those of excess waste and trash by using these as raw materials (UN ESCAP, 1997; Szaky, 2014). Through a combination of new ideas and the initiative of individuals and collectives, the productivity of the disadvantaged was a potentially underused resource that could improve lives and increase independence from donors on an unlimited scale. According to this understanding, productivity was limited to that occurring from locally available resources, since those are the ones that are independent of donors. Furthermore, this productivity occurs through trade or toil, which are the more literal understandings of what I meant by initiative. This set of beliefs about
the untapped value of the productivity of the disadvantaged in general could be easily reflected as a taken-for-granted assumption about the value of the productivity of the specific research participants. In this way, my prior experience might have contributed to an ideology that underlay my assumption about the value of productivity.

6.5.2 Social, institutional, and societal contexts

Although an ideology that valorizes independence from donors and appropriate technology is a plausible explanation for my assumption about the value of productivity, this seemed incomplete. After all, the productivity of the disadvantaged was not the only pathway to achieve independence from donors or achieve the promises of appropriate technology. For example, adequate state provision of services could achieve most of the benefits that I saw as important, yet I did not internalize that assumption. The realization that the explanation of my prior experiences did not fully account for my assumption about the value of productivity led me to look to a higher level to search for additional sources of influence. For this reason, I looked to the interpersonal, institutional, and societal contexts to which I had been exposed.

I conducted my doctoral studies through a prestigious Canadian university. When I was not in Zambia, I was based in a large metropolis in the global North. In my social circles, my institution, and in my community more generally there is significant evidence that people believed in productivity as an important value. This evidence appears in various forms and levels ranging from casual communication, through institutional mandates, to popular media. Among this evidence, I consider conversations with friends where one asks, “how was your day?” In response to this question, it is common to answer “productive” or “not productive.” Meanwhile, doctoral student colleagues have written blog posts with tips to increase productivity (Phillips, 2015). Admittedly, such tips seem useful to aspiring scholars for career success since academic programs demonstrate productivity through their websites (Sick Kids, 2016) and through peer-reviewed publications (Lozano et al., 2015) in apparent presentations of scientific capital (Langa, 2011). As job seekers, it would seem that we ignore the institutional imperative for productivity at our peril.

The imperative to be productive also circulates in the larger society. A recent article in the popular media lamented evidence of long work hours among Canadians, linking this to the need to be perceived as productive (Sorensen, 2015). Interestingly, the author framed his argument
without ever questioning the value of productivity; instead, he argued that fewer work hours could increase (the unexamined value that is) productivity.

Values that are so deeply held as to not require explanation are the exact ones that require social science examination. In a historical sociological study to question how productivity is understood in contemporary Canada, Foster (in press) describes the development of a “productivist ideational regime.” Foster describes this ideational regime as resting upon the intertwined notions that productivity is linked to economic growth and to prosperity. Although national-level growth is an abstract concept made possible through complicated statistical procedures, the notion that productivity is “a condition for prosperity” (Foster, in press: 219) circulates among individuals.

The societal belief in productivity as a condition for prosperity maps quite closely to my assumption regarding the potential for the creation of valuable products through the productivity of the disadvantaged. This leads me to posit that the societal belief is related to my assumption. The influence of the societal belief in productivity on my own assumption would seem to contradict other values that I hold: as a self-professed opponent of neoliberal capitalism, I consciously ascribe to the alternatives to “productivist societies” (D’Alisa et al., 2015). The possible contradiction between my conscious views and my (unconscious) assumption supports Foster’s (in press) proposition that “the productivist ideational regime remains more or less intact. Even when it seems to be under assault, today as in the past, it is adapting. Even in anti-productivist critiques, productivism is there, in traces” (p. 226).

6.5.3 Summary of possible underlying ideologies

In relating my assumption regarding the value of productivity to considerations outside the dissertation research, I identified two levels of analytic interest. In both my prior professional experiences and the interpersonal, institutional, and societal contexts to which I have been exposed, there is evidence of conditions that would be conducive to developing a set of beliefs (i.e., an ideology) in which the productivity of individuals is an important, positive value. Although my exposure to Canadian contexts could have reinforced an ideology that productivity was important for all individuals, my professional experiences in the global South could have contributed to an ideology about the value of productivity among the disadvantaged.
6.6 Alternative perspectives on productivity

In this reflexive analysis I have illuminated the way in which the “unproductive orientation” that I had perceived of the participants was constructed on the scaffold of an assumption that I took into the research. My assumption about the value of productivity among the disadvantaged had a dual, mutually-reinforcing effect of (1) informing a value judgment towards the participants’ ways of interacting and (2) clashing with my expectations for the research such that I experienced disjunctures. Recognizing the ways in which I had constructed a perception of unproductive orientation – and then reacted strongly to it – incentivized me to reconsider the ways that productivity might be understood by participants. Through such a reconsideration, it is possible to use the reflexive analysis of disjunctures to suggest alternative perspectives that are more closely aligned to the worldviews of the participants.

In order to reconsider how productivity might be understood by the participants, I reviewed the interactions with participants, searching for ways in which productivity might be enacted or discussed. Through this review I have identified two possible alternative ways to see productivity: (1) through the building of helping relationships and (2) through the discursive demonstration of legitimacy that could be enabled by referencing productivity.

6.6.1 Productively building helping relationships

In order to identify alternative ways of seeing productivity, I returned to the foundations of the word. Oxford English Dictionary (2016) definitions of productivity, and its source adjective productive, all relate to the achievement of outputs or results, generally as a reflection of producing things. The definitions do not, however, specify the nature of the product. Through the data generation activities, the participants expressed that the products that were important to them were material resources (Cleaver et al., 2016c). The participants also expressed that these products could be acquired through help from others who had access to these resources (Cleaver et al., 2016b).

Although the participants were clear regarding their need for material resources (as valuable products) and their positive views of help (as a distribution mechanism), it was not immediately clear to me that the participants were active as producers in this dynamic. It was likely the assumption that I took into this research that impeded me from validating efforts from the
participants that were *hiding* in plain view: the participants’ frequent requests for material resources and discussions of *help* could have been part of a process of cultivating me as a potential helper (Cleaver et al., 2016b).

Just as the participants spoke of receiving *help* from other relations with access to material resources, I had access to material resources. When presented from this angle, it made perfect sense that the participants would strive to *produce* a relationship with me that could lead to *help*. I was initially unable to see these efforts as productive; indeed, I saw them as *unproductive*. My inability to see the participants’ interactions as productive was likely because they were premised on an understanding of productivity that differed from my own, but also be because they are premised on an understanding of the economy that is different from my own.

By reflexively analyzing my experiences of disjuncture, I see that my own assumption was founded upon a notion that the participants should rely exclusively on *locally available resources*, particularly those that could be acquired or created through *trade* or *toil*. According to this assumption, approaching *outside sources* like myself through the building of relationships and the presentation of a compelling case did not constitute a productive economic activity in order to acquire resources. While I would not accuse an entrepreneur of being unproductive for talking about business and trying to build a relationship with potential investors, I somehow saw the participants as unproductive for talking about their needs and trying to build a relationship with me. Likewise, as a researcher, it is unlikely that I would be accused of being unproductive in articulating and presenting a compelling case about the need for research which I think should be conducted, yet I saw the participants as being unproductive for requesting things they thought they needed.

Like many who are enculturated in the modern (i.e., post-Enlightenment) global North, I could have conceived human relations as fundamentally distinct from the economic activities of acquiring resources (Mauss, 1950/1990), despite seeing evidence of *economic relationships* in my own culture. In addition, I could have also had a different self-conception of my fit into the economy of the communities where I did my research than my participants had of me. Whereas I saw my role as *knowledge generation*, the participants could have seen my role as *help provision*. By returning to the actual experiences of the research, and peeling back the layers of
how things could or should fit together, it seems highly plausible that the participants were being productive during the data generation through their efforts to build helping relationships.

6.6.2 Referencing productivity: a discursive demonstration of legitimacy

Participants in this research spoke explicitly about productivity in their accounts of help, yet they did this in ways that I assessed to be unproductive. Participants spoke on multiple occasions about how people with resources should provide help (gifts of material resources) so that the participants could help themselves. I initially understood these references to helping oneself to be expressions of desire to be productive according the understanding that productivity entails the use of available resources to make tangible products. According to that understanding, the mechanisms for productivity were often absent from the accounts, or somewhat confusing within them. Upon further review, the participants’ references to the ways in which gifts and grants would allow them to help themselves seemed to serve a function that was more discursive than it was intentional.

Participants spoke about helping themselves in general terms with few details, but also in more specific terms that included confusing details. One example of a participant speaking in general terms was a woman with leprosy claiming to me that “you can help us so that we can also help ourselves.” In this case, the participant specified that help was “a little something” and justified this help on the basis of her suffering. By contrast, the participant never explained the way in which the “little something” would enable her to help herself, even after a series of follow questions. An example of a participant offering a specific, but confusing, description of help to help oneself was offered by an older man who described himself as blind. This participant proposed that a monetary gift would allow him to hire a person to assist him with fishing and farming in order to acquire food. The participant’s desire to access more and better food seemed logical, but the notion that he would engage in the food production himself seemed unlikely given his visual impairment, the physically-intensive local techniques for fishing and farming, and his lack of explanation about how he would practically contribute to those tasks.

Presuming that my suspicion was correct that the participants were not planning to engage in “productive activity” through their references of helping themselves, why did they make these references? Just as my interest in productivity could be a reflection of social phenomena in North America, the participants’ expressions of productivity could be influenced by phenomena
relevant to their situation. In constructionist research, “participants are subjects, objects, and actors” (Deutsch, 2004: 889) who are likely to say the things they do according to a given rationale, whether or not they articulate this rationale or are even consciously aware of it.

In Zambia, there have been efforts by government and NGOs to promote an ethos of “self help” among citizens (Drinkwater, 1994; ReliefWeb, 2006), making the receipt of resources contingent upon recipients aligning themselves with program goals of self help. If the participants had been exposed to community development programming premised upon a self help philosophy, it is possible that they were aware of the importance of aligning their presentation of self to program goals of self help (Swidler and Watkins, 2009). The participants in this research often did not distinguish between programs and the frontline people who were responsible for implementing them, such that I could have resembled a program, in the sense that I was a person with some resources and power who was responsible for an agenda upon which I had some control.

Considering that I presented the research as a collaborative activity with potential benefits, it is quite reasonable that the participants aligned their presentation of self to their interpretation of collaboration and benefits, based upon past experience of what these things might mean. Given this dynamic, presenting oneself as productive through the willingness to help oneself (Cleaver et al., 2016b; Cleaver et al., 2016c) would seem to be a promising strategy to demonstrate legitimacy as a potential recipient in my program. For participants, it is quite possible that being a recipient in my program and a participant in my study were literally one-and-the-same. In this sense, referencing productivity as a discursive demonstration of legitimacy is completely logical, even though it seemed counterintuitive to me during fieldwork and early data analysis.

6.6.3 Summarizing alternative perspectives on productivity

By reviewing the interactions with participants, I was able to identify two alternative ways in which productivity could be understood. One way to understand productivity is through the potential building of helping relationships, where participants might devote energy to nurturing relationships that could lead to valuable products. Another way to understand productivity is through its discursive power to demonstrate legitimacy as a potential recipient of help through the willingness to be productive and help oneself. The second way to understand productivity complements the first in the sense that the discursive presentation of a willingness to be productive might contribute to the building of helping relationships.
6.7 Using the reflexive analysis to move beyond the disjunctures: considerations, implications, and limitations

From the disjunctures experienced during conduct of research, I have used reflexivity to do the following: describe an assumption that I took into the research, identify ideologies that might lie behind that assumption, and propose alternatives ways of understanding productivity based on the situation of the participants. Based upon the totality of this reflexive analysis, I now discuss the considerations for this research, the implications for other research on disability in the global South, and the limitations of this analysis.

6.7.1 Considerations for this research

Earlier iterations of the reflexive analysis described in this paper were essential to the analysis of empirical data from this research. Prior to having considered the ways in which I might have approached this research with an expectation of the participants’ style of interaction, I was concerned that my research involvement could increase the participants’ dependence on wealthy donors, furthering their disadvantage, and accentuating their subjugation. Through the reflexive analysis developed more fully in this paper, I was better able to understand the assumption that I took into the research and the ideologies that might lie behind it. This understanding created an opportunity to think differently about the participants’ interactions, and therefore see the entire project in a new way.

With the opportunity to understand productivity differently, it was possible for me to propose logical and coherent alternative ways to be productive and talk of productivity that could have been more consistent with the worldviews of the participants. The possible alternative ways of doing and speaking about productivity were instructive for my experience of conducting a research project informed by elements of participatory research (Herr and Anderson, 2005). Participatory research entails collaboration between researchers and participants towards practical goals, an endeavour that seems hard to imagine if the research and participants do not share a similar understanding of collaboration and productivity. The experience of this research was that participatory research was not possible within the timeframe of the project. Although adherence to participatory research principles was undoubtedly inhibited in this project by multiple levels of structural factors (Cleaver et al., 2016a), divergent understandings of productivity between researcher and participants could have further undermined this possibility.
Given that this project was conducted in a context where I experienced an advantageous power dynamic as a researcher in a position of privilege, I see it as my responsibility to better understand the participants’ interpretations of initiative, collaboration, contribution, and productivity. Through further interaction, it is possible that I will learn that these concepts are not important to the participants, but from the interactions thus far it seems like it is more likely that these are important, but understood in alternative ways.

6.7.2 Implications for postcolonial disability research

Postcolonial disability scholars point to the ways in which the most prominent understandings of disability for research, policy, and practice are those developed according to the concerns and realities of the global North (Grech 2009; Miles 2007). Although this study was designed to challenge the postcolonial “binaristic hierarchy” (Ashcroft et al. 2007: 124) of global North and global South, it was also undeniably influenced by this arrangement. The realities of the postcolonial world were likely relevant to this study through the combination of economic and epistemological factors, especially those related to my positionality as a rehabilitation professional and researcher from the global North conducting research with persons with disabilities in the global South.

In this dissertation research project, the disjunctures that I experienced were likely influenced by the realities of the postcolonial world. These disjunctures provided an incentive to conduct a reflexive analysis to identify productivity as an assumption that I took into the research, drawing attention to deeply held values that were otherwise not apparent. At very least, a small number of other researchers investigating disability in South Africa (which is close to, and geographically similar to, Zambia) have also considered productivity.

In one study, the researchers approached productivity in a manner that was very consistent to assumption that I carried into my research. Van Niekerk, Lorenzo, & Mdlokolo (2006) conducted entrepreneurial training and participatory research in South Africa with disability groups (also published as Lorenzo et al. 2007). Similar to my research, Van Niekerk et al. (2006) also found that material resources were important to the participants. For these researchers, however, the participants’ stated need for material resources was used to justify the impersonal exchange of knowledge to inform market-driven economic participation. According to Van Niekerk et al. (2006), participation in the entrepreneurial training “afforded [the participants with
disabilities] the opportunity to become productive members of their community and to contribute financially to the economic independence of their respective families” (p. 329). Yet this intervention was not successful for all participating groups and individuals. Among the challenges that reduced the program’s effectiveness, the authors cite project facilitators’ “compassion for the members of the group which led to behaviour which fostered dependence as opposed to empowerment” (p 328). Although possible, it does seem unlikely that the groups and individuals with merciless facilitators became empowered profit-generating entrepreneurs, while those with compassionate facilitators degenerated into disempowered and dependent entrepreneurial calamities. More likely, some compassionate behaviours led to a mixture of results that depended upon the context and the people involved.

Van Niekerk et al. ground their approach to productivity to international development and rehabilitation (Lorenzo et al. 2007), disciplines which might tend to encourage the notion of humans as individualistic economic agents. Interestingly, Van Niekerk et al. (2006) also base their approach on the traditional African philosophy of Ubuntu, whereby contributions to the community were necessary for individual belonging (p. 326). What is important to note, is that Van Niekerk et al. (2006) seem to only consider the contributions resulting from a productivity that is understood as resulting from trade or toil.

Meanwhile, in their study on disability grants, also in South Africa, Hansen and Sait (2011) present the relation of disability, Ubuntu, and productivity in a different light. According to Hansen and Sait (2011), persons with disabilities can support their communities and build connections by sharing state-sponsored social welfare resources. This latter understanding of productivity and contribution might be closer to the understandings practiced by the participants in my research. Using an acquisition method that Van Niekerk et al. (2006) might consider to be disempowering and dependence-inducing, the participants in Hansen and Sait’s (2011) research contribute important resources to their neighbours “in a practice that has to do with sharing wealth and building relationships vis-à-vis others” (p. 102).

Like my research, these two studies in South Africa also occur in a postcolonial world, at very least because of the overlay of Ubuntu with market capitalism and the welfare programming of the nation-state. Whereas the potentially conflicting perspectives of productivity between Van Niekerk et al. (2006) and Hansen and Sait (2011) occurred between different researchers and
research projects, the conflicting perspectives in my research occurred within a single project. Through this experience, I am well-placed to encourage others who are conducting postcolonial disability research to focus more attention towards their own understandings of productivity and the ways that this might be different from the understandings of the research participants.

6.7.3 Limitations of this analysis

Reflexivity has been critiqued as an exercise where researchers can “fall into an infinite regress of excessive self-analysis” (Finlay, 2002: 532). Such critiques are obvious concerns. On the flip side, reflexivity is seen as an essential element of research conducted from constructionist epistemologies (Breuer and Roth, 2003) and in the service of social justice (Hall, 1996). For this reason, it cannot be ignored. Weighing the concerns about reflexivity with its necessity and its potential compels me to identify the limitations of this analysis.

This reflexive analysis is not intended to be deterministic. Instead, it provides an opening for further considerations. The possibility that productivity was embedded within this dissertation project and yet invisible is adequate reason for increased attention. Following productivity along a reflexively analytic line through specific experiences and interpersonal, institutional, and societal influences is an admittedly narrow path, but an important one given the potential hegemonic power of an ideational regime of productivity. The proposition of how productivity might be understood from the participants’ positions is useful to provide alternative perspectives about productivity. Like all knowledge generated in a constructionist epistemology, this reflexive analysis is partial and contextual. Nonetheless, its value to illuminate the taken-for-granted outweighs its limitations.

6.8 Conclusion

Through this reflexive analysis of disjunctures experienced during doctoral dissertation research on disability in Western Zambia, it was possible to identify a deeply held assumption about the value of productivity that I had as the researcher. Identification of the ways in which productivity can be a helpful resource or a problematic imposition can contribute to improved postcolonial disability research. Researchers involved with postcolonial disability research can deepen the insight generated from their work through the use of reflexive analysis, especially as it relates to the ways in which conceptions of productivity might effect their work.
6.9 References


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Chapter 7

Research principles and research experiences: critical reflection on conducting a PhD dissertation on global health and disability

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Abstract

This article is a presentation of insights gained through critical reflection on the experience of doctoral dissertation research on disability in Western Zambia. The framework guiding this critical reflection is the Principles for Global Health Research released by the Canadian Coalition for Global Health Research (CCGHR) in 2015. These six interrelated principles were developed in order to inform and foster research that better and more explicitly addresses health inequities. The principles are: humility, responsiveness to the causes of inequities, commitment to the future, inclusion, authentic partnering, and shared benefits.

The insights gained through this analysis illuminated power dynamics that created barriers to fulfilling the Principles for Global Health Research. The power dynamics identified were rooted in structural arrangements. Specifically, these structural arrangements were inherent in research conducted from a position of privilege or inherent in a doctoral program. The identification of these insights and power dynamics informs next steps for this project in Western Zambia as well as considerations for current and prospective doctoral student researchers.
7 Research principles and research experiences: critical reflection on conducting a PhD dissertation on global health and disability

7.1 Introduction

This study could lead to some possible benefits for you or your community… The study is a student research project to increase understanding and will not include any direct material benefits such as money or food rations.

Information letter for participants in disability research in Western Zambia

When I look back at the study information that I shared with individuals considering participation in my doctoral dissertation research, I realize that many of these individuals may have understood some of this information to be contradictory. For the potential participants, members of disability groups in Western Zambia whose main expressed concern was poverty, it could have been hard to imagine a potential benefit that was unrelated to money or food. For me, a person of privilege from Canada who came of age in the era of a knowledge economy (Powell & Snellman, 2004), there was a strong relation between the production of ‘increased understanding’ and new possibilities for advancing social justice. These two disparate perspectives were in tension throughout the dissertation research process. This lack of harmonization is a truth that I find painful, yet compelling to explore, as the person who initiated this project with equitable participation of participants as a central concern.

The primary incentive for me to engage in this research was to address inequity: specifically, inequities faced by persons with disabilities in the global South. Worldwide, there are tremendous disparities rooted in an unequal distribution of power and resources, which itself is a result of the international political economy and systems of governance (Ottersen et al., 2014). Beyond this, it is likely that persons with disabilities face even more challenges than non-disabled populations of the global South (World Health Organization et al., 2011).

Unfortunately, even well-intentioned research is not guaranteed to reverse inequities given that ‘research activities have the potential to worsen, rather than address these injustices’ (Canadian Coalition for Global Health Research, 2015:1). The notion that research can perpetuate inequity, and that there could be different expectations with respect to my research based upon inequitable
disadvantages, was a realization that prompted the question: what does my doctoral research look like when viewed with an equity lens?

The purpose of this paper is to share insights about the conduct of doctoral-level research through a critical reflection of my own dissertation experience using a global health research principles framework grounded in a concern for equity.

7.2 The Principles for Global Health Research as a framework grounded in equity

In 2015, the Canadian Coalition for Global Health Research (CCGHR) released a set of six interrelated principles to inform research efforts to promote global health equity: humility, responsiveness to causes of inequities, commitment to the future, inclusion, authentic partnering, and shared benefits. These principles were developed through an evidence-informed process, with an ethos of solidarity together with those experiencing the devastating effects of systematic health injustices. Moreover, these principles reflect that research is not conducted outside of the frame of power relations that creates health inequities, noting that researchers must face the ‘mutual entanglement in the structures and processes that contribute to avoidable inequities’ (CCGHR, 2015:9). The Principles for Global Health Research were developed to ‘offer a set of practical tools…to inform practice, spark dialogue, and inspire reflection’ (CCGHR, 2015:1).

That the principles were developed by a Canadian global health organization has undoubtedly influenced their perspective: Canada is a settler colonist country that benefits economically from the current global order, but is also small enough to understand its weaker geopolitical situation relative to larger imperialist countries. I chose to use the principles as the framework for critical reflection on my global health doctoral dissertation since they align philosophically with my baseline values, and because they were explicitly designed for such uses. The dissertation experience that I reflect on spans from development of the research protocol through to dissemination and preparation for defense. To develop the insights presented in this paper, I engaged in an iterative process of analyzing data from the study, reviewing the principles, and discussing tensions from the dissertation fieldwork activities with my supervisory committee members.
Below I present this analysis in four parts. First, I describe the context, objective, and structure of the dissertation research. This section is followed by the critical reflections organized according to the six Principles for Global Health Research and the insights that they generated. I then use these insights to illuminate ways in which structured power dynamics influenced the possibilities of the doctoral dissertation. Finally, I discuss the implications, including the next steps for this project, recommendations for doctoral student researchers, and some limitations to the analysis.

7.3 Description of the Dissertation Research

Here I describe the context, objective, and structure of the dissertation research. The context is drawn out according to my underlying motivations and the conversion of these into a research protocol. The objective is described as per the research protocol. The structure of the research is described through an overview of the study design and a summary of the methods.

7.3.1 The underlying motivations

My pathway into research began as a rehabilitation professional (a physiotherapist) from the global North developing programs for persons with disabilities in the global South. Through these experiences, I slowly came to realize that ‘my patients’ often did not see their bodies, disability, health, and society in the same ways I did. Furthermore, having been exposed to community-based rehabilitation as the pre-eminent strategy for global health, I was familiar with the goal of empowering ‘people with disabilities and their families by promoting their inclusion and participation in development and decision-making processes,’ (World Health Organization et al., 2010:12). However, I learned through experience that the aspirations of empowerment, inclusion, and participation were elusive endeavours in practice. Over time, it became apparent to me that the problems that people faced, and my inability to respond effectively, were manifestations of phenomena that were systemic and pervasive, demanding consideration at multiple levels ranging from the interpersonal to the transnational.

As a foreign national simultaneously engaged in management and front-line work in the global South, it was apparent that the multiple levels of consideration were interconnected. Since I worked in non-governmental organizations that were focused on Southern problems but fueled by Northern charity, I was exposed to individuals as archetypical representatives of a systemic transnational dynamic. In general, my patients were aware that the world was a systematically
unequal place where they faced limited opportunities and the daily realities of harsh pragmatism. By contrast, similar perspectives were rare among the donors who funded the programs in which I worked. For the donors, the patients’ situations were the product of unfortunate circumstance that could be changed through charity. That the donors had ample resources for their excessive personal consumption, with a little extra available for donations, was often expressed as a product of good fortune, but never one of unjust structural privilege. Although this perspective allowed space for compassion, it did not further a sense of justice or collective solidarity.

Working at the boundary of global inequity with the systematically privileged of the global North on one side, and the systematically constrained of the global South on the other, made visible my ‘mutual entanglement’ (CCGHR, 2015:9). Not only was front-line work constrained by avoidable inequities, it was dependent upon structures and processes that created these same inequities. This position of dependence was therefore not advantageous for challenging these structures and processes directly.

On the other hand, being at the front-line provided an advantage: the perspective of seeing actual faces, personalities, and worldviews on both sides was a vantage point for creating strategies that might synergistically address both realities. Even when operating at the boundary, however, my identity remained that of privileged Northerner. This privilege is a resource that can be used, but it is also a threat to effectiveness: like the donors of my former employers, this position of comfort is one from which a person can ignore certain structures, processes, and perspectives. I propose that working closer to the ground can counter-balance this potential for ignorance, but that this grassroots work requires the consideration of multiple levels to be effective. This is especially true given that my exposure to situations of shocking tragedy and oppression were effectively a micro-representation of those that occur in other places throughout the world, primarily triggered by the same higher-level phenomena (Ottersen et al., 2014).

In order to operate closer to the grassroots level, but simultaneously come to better understand the situation at multiple levels, I sought to enroll in a doctoral research (PhD) program. In pursuing a PhD, I followed the precedent of students from the global North who focused their dissertations on disability in the global South (e.g., Aldersey, 2013; Berghs, 2011; Burck, 1989; Grech, 2011). My goal was to find an arrangement where knowledge generation and practical action at multiple levels were seen as complementary, and could therefore be pursued
simultaneously. In the interest of transparency, I must also note that through doctoral studies I was also seeking a degree for the purposes of career opportunities and accruing professional social capital.

7.3.2 Converting motivations into a dissertation

Doctoral programs are fundamentally focused on research, through the execution of a dissertation. Once enrolled in a promising program, I created a dissertation advisory committee that brought together scholars familiar with certain substantive (i.e., global health, disability, and rehabilitation), and methodological (qualitative, critical, and participatory strategies) areas. The early aim of this research was to study perspectives on disability and ways to improve the situations of those who experience it in a low resource setting. This seemed consistent with a grassroots orientation, potential for direct action, but also knowledge generation to capture the attention of audiences in the global North. Since one co-supervisor had colleagues and ongoing activities in Zambia, the research plans were developed for that country. Zambia is a lower middle-income country, with a gross domestic product per capital higher than many of its neighbours, but still quite low on the global scale (World Bank, 2014). The advisory committee ultimately included members from both Zambia and Canada.

In addition, the connections of the co-supervisor in Zambia allowed for important interaction with national-level disability advocates who suggested that I pursue this work in Zambia’s Western Province. Among the provinces of this relatively poor country, Western Province has the highest consistent level of poverty (Central Statistical Office, 2012). Western Province’s population is 85% rural (CSO, 2012), although the provincial capital of Mongu is a large town with urban amenities.

With the identification of a low resource jurisdiction for the research, advanced research methods training through the doctoral program, and the pragmatism required to craft a feasible research protocol, I was able to declare the study’s objective. The objective was to co-construct new ways of thinking about disability, and what to do about it, in the context of a North-South relationship between a North American-trained rehabilitation professional and disability communities and their members in Western Province, Zambia.
7.3.3 Study design and methods summary

This research was a qualitative study using a constructionist design (Silverman, 2006). The dissertation was further informed by a critical social science perspective (Eakin et al., 1996) and participatory research (Herr & Anderson, 2005). The methods of this study are described in greater detail elsewhere (Chapters 3 and 4) but I provide a brief summary here.

I conducted the fieldwork for this study with the support of five hired research assistants (all post-secondary students) from Western Zambia. The research participants were approached as groups rather than independent individuals. The participants were two groups of persons with disabilities; one urban, in the Provincial Capital of Mongu (22 participating members), and one in an outlying rural area (59 participating members). Data was generated through eight focus group discussions (FGDs) and 39 individual interviews, all of which were conducted in the participants’ languages of choice; typically in Silozi, but occasionally in another African language, English, or sign language. All data generation activities were semi-structured and led by me, with the assistance of the research assistants for logistics, simultaneous translation, and other supporting roles. The FGDs and individual interviews were audio-recorded and transcribed by the assistants according to a transcription guide that was developed for the study. I also made participant observation field notes during and/or after all interactive activities. After the fieldwork component, I returned to Canada to conduct the data analysis with the support of the dissertation advisory committee. The total time spent in Zambia included five months spent primarily in the capital of Lusaka in order to prepare for the fieldwork phase, followed by an additional six months in Western Province to conduct the fieldwork, and then another month split between Western Zambia and Lusaka six months after fieldwork for some preliminary follow-up activities.

7.4 Reflecting on this study using the Principles for Global Health Research as a framework

The six Principles for Global Health Research, produced by the Canadian Coalition for Global Health Research (CCGHR, 2015), are presented as parts of a wheel, with each principle sharing an equal connection to the underlying foundation of equity. Here I describe the research as it relates to each one of the principles, in turn. The insights gained from this review process are summarized in Table 7.1.
Table 7.1 – Insights gained through the review of a research project using the CCGHR Principles for Global Health Research (CCGHR, 2015)

<table>
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<th>Principle</th>
<th>Main insights</th>
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<tr>
<td>1. Humility</td>
<td>Assessing the practice of humility was challenging if not impossible due to the pre-existing power dynamic.</td>
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<td>2. Responsiveness to causes of inequities</td>
<td>Research was a tool to explore the structural aspects that underpin health inequities observed in practice, but did not lead to discernable change in the short-term.</td>
</tr>
<tr>
<td>3. Commitment to the future</td>
<td>The structure of doctoral dissertation research institutionalized the commitment to the student researcher’s future and the protection of research participants; but involved only a voluntary commitment to the futures of other stakeholders.</td>
</tr>
<tr>
<td>4. Inclusion</td>
<td>Inclusive research remained a challenge even though this principle was foundational to the project.</td>
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<tr>
<td>5. Authentic partnering</td>
<td>These research practice principles were undermined by:</td>
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<tr>
<td>6. Shared benefits</td>
<td>a) The structure of the doctoral program, and</td>
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<td></td>
<td>b) A power dynamic in which the student researcher’s concerns were centralized while those of participants were marginalized.</td>
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7.4.1 Humility

This principle is described as the destabilization of certainty in order to open oneself to deeper exploration of ‘values, beliefs, motivations, and assumptions’ (CCGHR 2015:9). In conducting this doctoral dissertation, I was stimulated to examine my deeply-held views by tensions felt viscerally while in the field, the challenge of making sense of the vast corpus of data, and additional readings during analysis. Although these activities are part of the operationalization of humility, the description of the principle entails a paradox: if we perpetually ‘[position] ourselves in a place of learning rather than knowing’ (CCGHR 2015:9), how can we know that we are practicing humility?

Beyond self-awareness, humility is ‘the quality of having a modest or low view of one’s importance’ (Oxford, 2016). Understood in this way, humility is likely to make a person more approachable, even in an ostensible situation of power. This sense of humility is possibly best epitomized by Ivan Illich’s (1990) suggestion that ‘If you insist on working with the poor…then at least work among the poor who can tell you to go to hell’ (p 320). During my fieldwork, I never had a participant tell me to ‘go to hell.’ Is this a sign that I acted with humility such that
my presence was comfortably received? Alternatively, might there have been a power structure that made it impossible for the participants to voice such a protest? Is it possible that no amount of humility can suffice to overcome some power structures? Given the ways that humility is described, I can confirm that I engaged in self-awareness behaviour, but consistent to the principle I remain unsure of the extent to which I effectively practiced humility.

7.4.2 Responsiveness to causes of inequity

This principle was the concern that motivated me to pursue doctoral studies. As previously described, the problems that I was striving to address as a rehabilitation provider were rooted in inequitable structural forces, yet the charity-based organizations in which I worked permitted the structural imbalances rather than challenging them. My dissertation was therefore designed to amplify different (disabled, Southern) voices in order to challenge a status quo where the privileged were able to ignore the perspectives of ‘the others.’ To achieve this goal, I aimed to present an alternative account of the situation of disability in the global South to privileged audiences. These audiences included my rehabilitation colleagues from the global North and non-governmental organization supporters.

Sensitizing privileged audiences to alternative perspectives about the structured transnational dynamic that privileges some at the expense of others is a long-term endeavour with a potentially unreceptive audience. Therefore, success will be difficult and take time. Despite my intent to respond to this cause of inequity, it remains to be seen as to whether the strategies I used will be effective in achieving this goal.

7.4.3 Commitment to the future

This principle is described primarily in terms of sustainability and global connectedness. In this spirit, the CCGHR (2015) calls on researchers to re-conceptualize timelines beyond the minimum requirements for research practice in order to ‘challenge the tendency to cycle through project-driven agendas’ and instead ‘leverage short-term or immediate opportunities within a long-term vision’ (p. 7). This principle challenges some of the fundamental considerations of doctoral studies. The first is the challenge of contributing to a long-term vision through an uncertain short-term commitment. The next challenge is the question ‘to whose future are we committed?’
My experience as a doctoral student has involved significant uncertainty. The conduct of the research itself entailed uncertainty as my plans evolved in ways that I could not foresee in response to new information that I learned as a student advancing through my academic program. Moreover, life beyond doctoral studies is even more uncertain, with my willingness and ability to engage in extensions of my doctoral work dependent upon unknown future opportunities. As an attempt to contribute to a long-term vision through this uncertain short-term commitment, I aligned my work to the maximum extent possible with one co-supervisor’s ongoing research program. This alignment was successful insofar as I was able to share country-specific information amassed as part of my fieldwork and contribute to strengthening Zambia-Canada health research relations (CCGHR, no date).

In both of the examples above, my contribution to the future of the co-supervisor’s research program aligned with my own interests, since I was also relying on the connections of this research program to further my own work. This raises the question ‘to whose future was I actually committed?’ As a capacity-building venture, doctoral studies focus upon the future of the student. Despite the potential contributions that I presented above, it was my future that was most likely to be positively influenced by the completion of this research and its successful defense. Due to the commitment to my own future, and the constant awareness that receipt of the doctoral degree is dependent upon program completion, the dictates of my institution were mainstreamed obligations. By contrast, concerns related to partners, the local economy, and the environment were optional, and addressed at my discretion. As I describe below, in moments of tension and conflict, the discretionary concerns towards the commitment to the future of others were insufficient to overcome the mainstreamed obligations that dictated the terms of program completion, and thus my commitment to my own future.

7.4.4 Inclusion

In parallel to being one of the Principles for Global Health Research, inclusion has long been a concern of persons with disabilities and a matter of interest in disability studies (Oliver & Barnes, 2010). Inclusion was foundational to this dissertation, and a constant challenge within it. Challenges with respect to inclusion emerged early in the research design process: during the preparation of the research ethics submission, there were foreseeable ethical issues related to
consent processes for potential adult participants with intellectual disabilities (a dilemma that ultimately did not arise during the conduct of the research).

By contrast, a different issue related to the inclusion of participants based upon ‘disability type’ was more difficult than foreseen: despite the intention and budget to hire sign language interpreters, I was unable to find a candidate to fulfill this role on a regular basis. For this reason, the participation of two members of the urban group who communicated primarily by sign language was reduced to an unwieldy process of communicating in focus group discussions through a shared piece of paper through which a research assistant tried to present a superficial running transcript of the dialogue while collecting comments and questions. Although the devotion of an employee to this task seemed like a reasonable compromise given the resources available, it did not allow the type of inclusive participation we sought to achieve. Reflecting back on the fieldwork, I also realized the extent to which I focused my inclusion efforts on disability as compared to the other areas of historical marginalization, such as ‘race, class, sex, ability, religion, sexual identity, Indigeneity, etc.’ (CCGHR 2015:5).

7.4.5 Authentic partnering

The principle of authentic partnering was a design consideration throughout the research process, with considerations of national-level and local-level partnerships. Like shared benefits, partnership is a central tenet of the participatory research paradigm (Herr & Anderson, 2005), which aligned with this project’s commitment to simultaneous knowledge generation and practical action.

The partnerships developed with national-level disabled persons’ organizations (DPOs) were of minor intensity but important. Because of these partnerships, the DPOs invited me to workshops to learn about national disability policy. The DPOs also shared connections that enabled me to begin work in Western Province. By contrast, there was little interest among the national-level DPOs to discuss the focus of the research or the practical impacts that the findings of various research questions could produce.

The greater challenge with respect to authentic partnering was at the level of the research participants. The desire for local-level partnerships was a key reason for designing the research around collective rather than individual participation: partnership seemed more achievable with
established collectives. I had hoped to develop the research questions and design together with these collectives, however, I did not have a pre-existing partnership with these types of grassroots groups, meaning that I would need to recruit them. In order to recruit groups for the research, I needed research ethics board approval, which required that I have research questions and a study design. These requirements eliminated the possibility that I could co-construct the research with the participants. As a compromise, the study was designed to allow the participants to influence processes related to data generation, with the intent that these initial steps of shared leadership would gain momentum into a dissemination phase that would better reflect authentic partnering.

In actuality, the process of partnering with the research participants was fraught with difficulty. Much of this was likely related to the extent to which the benefits of the research were shared. With the urban group, the process of executing research activities was relatively straightforward in that the prospective research plan was essentially approved by the group with suggestions regarding logistical details. The situation with the rural group was more complicated, and involved misunderstandings related to expectations. To the initial confusion of the research assistants and me, the rural group was loosely organized (Cleaver et al., 2016), and willing to adopt a structure that best suited the plans of the researchers. By contrast, the study team was under the impression that the rural group had a pre-existing structure. To prepare the data generation activities, the research assistants and I met with the nine leaders of the rural group, learning that the ‘membership’ of the group of ‘maybe a few dozen’ had inflated to over one hundred. I stated that we would be unable to work with a group that large and would have to review how and whether we could complete the research in this community. The leaders responded by offering to reduce the number of members while I offered to increase the size of the first round of focus group discussions. Making this adjustment felt unusual; according to the research protocol, the issue never should have arisen as I had been seeking to recruit an established group of a much smaller size. By this stage in the fieldwork it was becoming apparent that groups of persons with disabilities in rural Western Zambia were rare, increasing my willingness to allow that the group met criteria I had established prior to having developed extensive knowledge of the research context.

When the first round focus group discussions were held a few days after meeting the leaders, a larger number of individuals arrived than we were able to include. My initial reaction was to
return to the leaders to ask them to limit the participation to the group’s members. It was only at that point that I realized that the group was not a formal entity and that many in the community were presenting themselves as disabled in order to participate in the research. The question of who was, or was not, disabled was contentious within the rural community due to previous charitable distributions. According to participants, fixed amounts of food and clothing had been ‘divided among all the disabled,’ causing many to claim disability status. Those with more severe disabilities contended that the inclusion of less disabled people meant that the ‘real disabled’ did not receive their fair share.

With this situation of contentious eligibility, I realized that the leaders were now caught in an uncomfortable position. The leaders had brokered my involvement in the community, which was seen as a positive, but were also gatekeepers to the research, which made them potential targets for antagonism. Prior to that point I had not seen the fundamental misunderstanding that had created this situation: whereas I expected the group to have a clear structure based upon local dynamics and priorities, the community members expected me to arrive with clearly-defined criteria about the individuals I would ‘help.’ From the comments of the leaders, there had been no precedent for a visitor to ask the community about its established social structures and use this as a point of departure for engagement; this strategy seemed disorganized and cryptic to the leaders. Since the explanations that I provided did not seem plausible, the leaders frequently requested that I re-explain my plans.

To fulfill my research plan of completing interviews and an additional focus group discussion, I selected the participants for these remaining data generation activities, primarily according to characteristics that made sense to me. Although successful for the purpose of generating the data that I needed, this strategy was not a reflection of authentic partnering.

7.4.6 Shared benefits

Like authentic partnering, this principle was a consideration from the start of this dissertation. As a researcher, I felt that my work could lead to products that were consistent with my task of knowledge generation and also of use to national-level disability DPOs or the participating research groups. More specifically, I had envisioned that the data generated and analysed for my dissertation could be re-packaged as reports or presentations for advocacy activities or other purposes. I foresaw that such ‘academic products’ would be a shared benefit for the national- and
local-level stakeholders. During the fieldwork components of this dissertation research, it became apparent that the potential of these academic products did not resonate with the people with whom I sought to ally. The national-level colleagues seemed indifferent to these possibilities while the members of the participating groups remained silent through the repeated suggestions of using research findings to inform collective action.

The lack of interest in academic products from the participating groups was not indicative of a lack of ideas about how I could produce relevant benefits. Their recommendations to me included: visiting government and NGO offices and telling them that persons with disabilities required more resources; taking their photographs and returning to my country in order to collect donations; providing loans; or buying equipment. At the time of data generation, I was able to hear all of these requests for material resources, yet I distanced myself from every one: their requests to me reminded me of the dynamic between privileged donors and downtrodden persons with disabilities that I had witnessed in other global South locations. I saw this dynamic as one in which the participants were willing to forego agency in order to meet immediate basic needs. In this dynamic, I saw myself at risk of being drawn to the easy solutions of using my resources to proudly meet immediate requests. I saw the potential that this dynamic could overshadow my awareness that the issue of the disadvantage of disability was bigger than these two groups, and that my privilege to engage in easy solutions was one that was granted by an oppressive transnational structure.

I thought that I had pre-emptively created distance from such requests by stating that there would be no material benefits for participants in the consent process, and attempted to maintain the distance in an active and ongoing manner during the interactions by trying to direct the discussion to other topics. To my frustration, these requests for resources continued throughout the duration of fieldwork.

With some time for reflection, I now see the participants’ requests in a different light. Then, as now, I saw the request stemming from recognition that I had access to money and material resources while they did not. The change in my perspective relates to the extent to which the participants were executing agency. During the fieldwork activities, I thought that the participants were ignoring the terms of the consent process because they did not know what else to do. At the time I was unable to see my declaration of the potential benefits to be one that was
made from a position of power, such that the participants might not have felt able to overtly challenge that declaration lest it mean that they risk losing access to important potential benefits. Instead, the participants responded to the opportunities and burdens of research participation with strategies of subtle acquiescence and resistance (Scott, 1985). In the case of this research, for many of the participants it seems that the main strategy was participating in the research in order to voice their need for material resources as the answer to almost every question.

In the shadow of these challenges, an important benefit that I was seeking (data generation in order to complete a PhD) was achieved, while most of the suggestions of the research participants were left unaddressed. However, there was one clear and unforeseen benefit for the urban group. Through an oversight, neither the chair of the urban group nor I had thought of contacting the local traditional leader prior to beginning data generation. Late in the fieldwork process we realized the omission and arranged a meeting. This initial meeting led to an invitation to the traditional court. While at the court, the area traditional leaders asked the chair what they could do for the group, at which point she suggested they could be given a plot of land. With land allocation largely in the jurisdiction of the traditional leadership, the request was granted.

The land acquisition was clearly a positive development for the urban group. My involvement had facilitated the acquisition of this land, but not through my research in the sense of data, analysis, or knowledge generation: although I was present at the traditional court, the leaders were more interested in the needs of the group than they were about my research. My value to the process seemed to be that I was an interesting international visitor who was attached to this group, providing the group with a sense of importance in the eyes of the leaders. In this case, the benefit of the land acquisition was shared between the group and me through reciprocity: the group had participated in the research for my benefit, while my presence had created the impetus for meetings that ultimately benefited the group.

7.5 The Principles for Global Health Research and structural power dynamics

The insights gained through reflection on the Principles for Global Health Research have made it possible to see how power dynamics created barriers to operationalizing the principles. The challenges were different for each principle, with some more interrelated than others. This project was designed to be responsive to causes of inequities, but it will take time to see if that
goal was achieved. The principle of humility is difficult to assess, so even though I recognize its importance, I remain uncertain as to whether I effectively practiced humility. The principle of inclusion was foundational, yet the operationalization was incomplete. The principles of authentic partnership, shared benefits, and a commitment to the future (of the participants) were the most elusive. It is the insights from these latter principles that were most instrumental in illuminating the relevant power dynamics. The power dynamics identified were rooted in structural arrangements, specifically, those that are inherent in research conducted from a position of privilege or inherent in a doctoral program.

7.5.1 Power dynamics resulting from being a privileged researcher

Because of my positionality as a person of privilege, I had access to resources that were desired by participants and difficult for them to acquire through other means. This scenario created an incentive for them to gravitate towards me on terms that were mostly under my control. The resources in question included money and its associated purchasing power, acquaintances with money, and easier entry to governmental and non-governmental organization offices. With a lack of feasible alternatives, it is likely that at least some of the participants engaged in the research with the hope of acquiring resources through me. In this type of situation, there is little reason to believe that a consent process stating that there would be no material benefits to participation would be sufficient to counter such hopes. Conversely, as the researcher, I depended upon the participants for data generation but could have searched for other participants if the first groups refused to consent, or redesigned the study if unable to find participants who were willing to engage on my terms. The entire arrangement meant a direct power imbalance tilted in my favour as the researcher, as is demonstrated in Figure 7.1. This direct power imbalance challenged authentic partnering and skewed the possibilities for research benefits and future orientation in my favour.

7.5.2 Power dynamics embedded in a doctoral program

Despite the imbalance described above, I was not a completely independent actor as a doctoral student researcher: I had to respond to the constraints imposed upon me by the academic program. These constraints were then transmitted through me to the research setting where they manifested themselves through the pathway of pragmatic decisions. The constraints imposed upon me included the privileging of ‘academic products’ as outcomes of the research, the
expected order of operations, and the program time-limit. The sum of these constraints equated to the de-prioritization of the global health principles relative to other considerations (see Figure 7.2).

Figure 7.1 – Power dynamics resulting from a researcher in a position of privilege.

Figure 7.2 – Power dynamics embedded in a doctoral program.
The *order of operations* refers to the overall sequence of activities for this study. According to the norms of the graduate department, the study protocol was developed in its entirety before the recruitment of participants. This sequence then meant that it was not possible to develop the research questions and the study design according to the inputs, preferences, and priorities of the research participants. Since the protocol was developed prior to contact, I had to foresee the benefits that might be created and try to anticipate which ones might be shared as part of a commitment to the participants’ futures.

The institutional structure in which I operated as a student privileged ‘academic products,’ such as journal articles, conference abstracts, and a completed dissertation that was ‘an original contribution to knowledge [such that I] demonstrated an appropriate level of scholarship in [my] chosen field’ (Rehabilitation Sciences Institute, 2015:39). In this structure, engaging in different types of activities (even if these are the practical concerns of research participants) is seen as an optional possibility, but not a necessity. Given these realities, my search for shared benefits began with the premise that these should be research findings that could be modified into academic products that would be relevant for local and practical action. The foreseen modifications were reports or presentations of the research findings. In the course of fieldwork, the participants never expressed that academic products were useful to them, and when I suggested this possibility the participants went silent or changed the subject. With the one foreseen shared benefit no longer compelling, would it be possible to identify others?

With the constraints of the *program time limit*, it was not possible to develop an alternative vision for shared benefits since there was little room for the evolution of authentic partnering. The time limits of this dissertation were driven primarily by the term of the student funding package and the academic department’s expected time to completion policy. Even though the above factors led to a five-year window, comparatively generous relative to other PhD programs, the program expectations of course work, comprehensive exams, and a substantial dissertation left little available time for authentic partnering leading to shared benefits.

### 7.6 Implications

#### 7.6.1 Next steps for this project
The most important consideration of this analysis is the local practical relevance of this research for the participants, such that there is equity with respect to the benefits of the project. As the CCGHR (2015) states, there is a need for ‘explicit efforts to identify and honour the needs of all partners involved in [global health research] with an intention to ensure those with the greatest need benefit the most’ (p6). Among the stakeholders in this study, it is the participants who have the greatest needs, and they have clearly identified that their needs are in the form of material resources. The challenge for ongoing engagement with these communities after the completion of my doctorate will be to find ways to contribute to the needs for material resources from a position different than that of the detached privileged donor.

For the most part, I foresee that the help that I can provide to secure material resources will likely be me joining the participants in order to ‘legitimize’ the same claims that they have already made to government agencies and non-governmental organizations in my absence. That I could be useful in this way is problematic; it reflects and reinforces an ongoing neo-colonial arrangement of power and privilege such that the allyship of a White foreigner is seen as necessary for success. Conversely, it also brings researcher and participants together in ways that could more realistically involve authentic partnering, which can serve to challenge that same neo-colonial arrangement.

Since the return to Western Zambia will not occur until after the completion of my doctoral program, my continued involvement is at the mercy of competing opportunities. What will be the implications for this plan if I am offered employment prior to fulfilling these responsibilities? Fortunately, the possibility of building upon the context-specific knowledge that I acquired during the research and the connections that were made is likely in my professional interest. Therefore, a return to Western Zambia would be valuable for my own commitment to my future in addition to the possibility of pursuing authentic partnering and shared benefits. This situation admittedly might not be the same for other doctoral students after the completion of their degrees.

7.6.2 Considerations for doctoral student researchers

The insights stemming from my doctoral dissertation experience are not unique to PhD students, yet they are most directly relevant to this constituency. For this reason, I have chosen to focus upon considerations that could be enacted by future or current doctoral student researchers. Such
considerations could be valuable for those who have chosen to pursue global health doctoral studies in order to ‘approach [their] research with ideals of social justice, health as a human right, a sensitivity to the past failings of development, and a desire to reduce global disparities’ (Walker et al., 2006). Researchers in other positions are of course welcome to modify these considerations according to their specific situation.

Doctoral student researchers aiming to fulfill the Principles for Global Health Research can consider the use of various strategies singularly or in combination. Strategies include the centralization of the principles from an early stage, the identification of the extent to which the principles can be completed within the dissertation, and an overall study plan that consists of a series of smaller projects.

Centralizing the global health research principles from an early stage can allow a doctoral student to incorporate these principles into all aspects of the dissertation. Although it is possible that the specific ways that the research would fulfill the principles would change over time, centralizing these concerns reduces the probability that they simply ‘fall out’ of the plans as the dissertation evolves. Reference to the principles can garner a sense of legitimacy of these concerns within the research community. Furthermore, a commitment to these principles at an early phase facilitates a clearer conceptualization of priorities that will help a prospective doctoral student researcher identify the program, supervisor, funding sources, and stakeholders that best align with their interests.

Identifying the extent to which the principles can be operationalized within the dissertation gives the doctoral student permission to determine what can be completed well and focus upon accomplishing these things. In some cases, it might be necessary to acknowledge that competing concerns impede the possibility of addressing all of the principles during the dissertation, such that additional follow up projects are necessary. Recognizing and communicating this situation could help the global health community more clearly address the difficulties and tensions related to the conduct of global health doctoral research for equity. In turn, this awareness could lead to the creation of structural changes that facilitate the possibility of ongoing commitments beyond the project life.

An overall study plan consisting of a series of smaller projects can increase the capacity of a dissertation to be responsive to on-the-ground realities while remaining systematic. This
conceptualization of a thesis is consistent with the ‘Cycles of Action and Reflection’ (Ladkin, 2004:540) that have been described by those engaged in participatory research. In practice, this could mean that there is initially a protocol for some initial descriptive stages of the dissertation, while additional protocols are developed in accordance to the first. Importantly, conceptualizing the plans as a series of smaller projects could create more space for stakeholders to influence the project as it progresses, changing the power dynamic from one where the decisions about the research are primarily made before the researcher enters the field.

7.6.3 Limitations of this paper

The implications described here were proximal to this project and the decisions of PhD student researchers: I did not address those that apply more directly to graduate departments, universities, funding bodies, research ethics boards, or other institutions. Also, since the critical reflection was grounded to my own situation as a doctoral student researcher, I did not attempt to speculate on the ways that things would be similar or different for researchers striving to address equity from other positionalities. It is researchers who are in these different positionalities who are best placed to assess the applicability of these insights for their respective cases. Finally, I approached this exercise using the Principles for Global Health Research as a post hoc framework; the insights and subsequent realizations could be different for researchers who declare and centre commitment to these particular principles from the outset.

7.7 Conclusion

The purpose of this paper was to share insights gained from reflecting upon the experience of conducting doctoral research on global health and disability. As demonstrated, the CCGHR Principles for Global Health Research offer a useful framework to reflect upon research conducted to address inequities. The insights gained through this reflection led to greater insight about how power dynamics rooted in structures created barriers to fulfilling the principles. Through greater awareness of the principles, the insights gleaned reflecting upon these, and the strategies that this reflection has informed, future doctoral students can position themselves to conduct research that is more effective at addressing systematic inequities.
7.8 References


Cleaver, S., Polatajko, H., et al. (submitted). Disability research in Western Zambia: “All of the problems of poverty and brought because of being disabled.” *Disability & Rehabilitation*.


Chapter 8

8  Integration and Conclusion

In this chapter I draw together the thesis by relating the purpose and objectives to summaries of the content presented in the manuscript chapters. These summaries are used to develop the key finding from the research, which is used in turn to inform a series of implications for various audiences, including considerations for future research. I close the thesis by presenting some limitations and concluding remarks.

8.1  Summary of the material from the manuscripts presented as per the study objectives

This thesis was guided by an overarching purpose: to co-construct new ways of thinking about disability, and what to do about it, in the context of a postcolonial encounter, involving a North American-trained rehabilitation professional and two disability groups and their members in Western Province, Zambia. This purpose was addressed using three objectives, which guided the development of individual manuscripts.

Each of the study objectives is presented below, followed by a summary of the manuscript(s) that addressed the objective.

8.1.1 Objective 1: To describe the unique context and nature of one urban and one rural disability group in Western Zambia, and explore these groups’ expressed concerns.

This objective is the primary focus of Chapter 4 where I presented the context and nature of each of the disability groups, and the expressed concerns of these groups.

The contexts of the groups’ respective communities were different as a function of the design of the study (urban and rural), yet there were additional contextual elements that appeared to be relevant. The urban group was developed in response to a government initiative and had a formal structure; meanwhile the rural group evolved from a leprosy treatment centre and was fluid in its membership structure. Each of these groups was structured in a manner that optimized the ability of the group to seek material resources according to its context. It appeared possible that it was
the structure of the groups, according to their contexts, that then shaped the parameters for membership; including the understanding who did, or did not, have a disability.

In terms of expressed concerns, poverty was the main concern of the participants in both communities in this research. The concern of poverty as a defining feature of the participants’ lives with disability in Western Zambia overshadowed other possible elements of life with a disability, including concerns directly related to impairments.

Participants spoke of the relation of poverty and disability in two main ways, either that poverty was an integral part of disability, or that disability set off a revised vicious circle of poverty. Participants presented poverty as consisting of the interrelated phenomena of a lack of material resources and a life of suffering. The predominance of the concern for poverty was consistent between groups and across demographics. Because of the predominance and consistency of this theme, there was not extensive analysis devoted to emergent themes or subtler differences in response patterns across or within groups.

8.1.2 Objective 2: To explore how strategies to improve the situation of persons with disabilities are framed within the accounts of participating disability groups in Western Zambia.

This objective is the primary focus of Chapter 5 where I presented help as the way that participants framed strategies to improve the situation of persons with disabilities in Western Zambia. Participants framed this as a strategy that has been ongoing, but one which should be increased and expanded through stronger connections with helpers. Like the concern for poverty, the single theme of help was predominant and consistent between groups and across demographics.

When framed as a strategy to improve the situation of persons with disabilities, participants referred to help as a gift or grant of material resources. Participants spoke about the way in which helpers saw needs and responded, and in a few exceptional instances there were participants who were helpers. Participants presented themselves as potential recipients of help in their interactions with me and provided specific suggestions about how I could help them. The underlying reason behind help was a relationship of expected compassion.
8.1.3 Objective 3: To critically reflect on the experience of conducting this thesis research through the lenses of (a) a critical social science perspective (CSSP), and (b) global health research ethics, in order to better understand the research process.

This objective is the primary focus of Chapters 6 and 7 where I presented critical reflections about the research process. In each case, the lens chosen for these critical reflections was consistent with a baseline methodological or theoretical commitment made at the time when the study was designed, although the specific lens and analytic structure was developed at a later stage. Each of sub-objectives (a and b) is consistent with one manuscript chapter of the thesis. Each of these is described in turn, before the two are synthesized to address the objective in its entirety.

8.1.3.1 Objective 3a: Using reflexivity guided by a CSSP to understand disjunctures

In Chapter 6 I described the disjunctures (a termed used by Mandel [2003]) that I experienced as the research participants spoke frequently about material resources and help: I had expected that the study would unfold a different way. My response to these disjunctures was frustration while in the research field, causing me to change the way that I interacted with people in the communities where the research took place. The disjunctures also caused me difficulty in the early data analysis phase since the data seemed wrong. The contradiction between the expected and the experienced attracted my attention, providing me with an incentive to conduct a reflexive analysis.

Guided by a critical social science perspective, as described by Eakin et al., (1996), I conducted a reflexive analysis of the assumptions that I took into to the research project, and the ideologies that could have underlain these assumptions. Through this analysis, I unpacked the experiences of disjuncture to find an assumption that I had made with respect to the value of the participants’ productivity. I understood productivity in terms of the participants pursuing their goals for valuable products using only local resources and their personal capacities for trade or toil. In reflecting on life experiences outside of the research, I was able to identify ways in which ideologies absorbed through professional contexts in the global South, and interpersonal, institutional, and societal contexts in the global North, might support the assumption that I took into the research. Having identified the assumption and underlying ideologies, I turned my
attention back to productivity, and proposed alternative perspectives of productivity that could be seen as more consistent to the participants’ interaction styles. These alternative perspectives included the possibility of seeing relationship-building for the purpose of securing help as a productive activity, as well as the possibility that participants used narrative presentations of self-help to demonstrate their legitimacy as potential beneficiaries.

8.1.3.2 Objective 3b: Using critical reflection guided by global health research ethics to share insights about research practice

In Chapter 7 I presented a critical reflection of the thesis research project using the CCGHR’s (2015) Principles for Global Health Research. Reflecting on the project, I noted that it was not clear as to whether I had fulfilled any of the six principles, but that the principles of authentic partnership, shared benefits, and a commitment to the future were particularly elusive. The analysis of the challenges related to these principles illuminated the presence of power dynamics operating in the research field. These power dynamics were rooted in structural arrangements. Specifically, the structural arrangements were those associated with a doctoral program and with research conducted from a position of privilege.

8.1.3.3 Synthesis of Objectives 3a and 3b

The analyses presented in Chapters 6 and 7 brought attention to power dynamics operating within the research context. Power dynamics operated in multiple complex ways in this study, with identifiable influences emanating from ideologies, institutions, positionalities, and the sense-making processes of those of us who engaged in the research. Recognizing these power dynamics is important to understanding this research, since data are generated through interaction in constructionist research, and interaction always occurs in contexts that must be explicitly recognized. These power dynamics influenced my approach to fieldwork and likely also influenced the ways that the participants acted and the things that they said.

Specifically, the participants’ emphatic and repeated talk of poverty and help were likely reflections in the data of the differences in positionality between researcher and participants. Given the power dynamics of my position as a mobile, privileged researcher with access to resources that the participants felt they needed, it is likely that the participants chose to “do help” (as per Section 5.3.2) in the research interactions as opposed to engaging on terms that would
challenge my authority and risk offending me. The research process was therefore influential in creating the context in which the researcher and participants generated data.

8.2 Key finding: disability, and what to do about it, can be seen as a single socio-economic phenomenon

This thesis was guided by an overarching purpose: to construct new ways of thinking about disability, and what to do about it, in the context of a postcolonial encounter, involving a North American-trained rehabilitation professional and two disability groups and their members in Western Province, Zambia.

The central aspect of the study purpose relates to “ways of thinking about disability, and what to do about it.” Through the empirical findings generated in this research, disability, and what to do about it, can be understood as a single, socio-economic phenomenon. Specifically, disability was presented as a problem with a readily available solution. The problem was an economic one (poverty) and the solution a social one (help). This key finding is supported by the participants’ main concern and their framing of strategies to improve their situation, but also in the way that the groups responded to their contextually unique situations to collectivize in order to seek resources. Life with disability therefore involves special attention to resources and relations, considerations that are so tightly interconnected as to be part of the same phenomenon. I relate this key finding to the dominant ways of understanding disability, and what to do about it, in Section 8.3, Implications.

This research was centrally grounded in a constructionist methodology, whereby it is recognized that knowledge is generated through the interaction of researcher and participants in a specific context. The contexts in which I conducted this research were those in which there was marked pre-existing material deprivation. In the context of the relationship of the researcher and the researched, each occupied a different positionality.

8.3 Implications of the study

Here I articulate implications of this research with respect to (1) policy, programming and practice, (2) disability theory, and (3) future research.
8.3.1 Implications for policy, programming, and practice

8.3.1.1 Implications for community-based rehabilitation (CBR)

As I presented in Chapter 1, CBR is laid out according to a matrix with five components, further divided into 25 elements (see Figure 1.1). Participants in this research framed strategies to improve their situation as help. In considering the five components, it is possible that help could be understood to be a part of any one of three: livelihood, social, or empowerment. When we consider help at the level of the 25 elements, it does not clearly fit into any. It is possible that CBR programming that covered many or all of the elements might provide a given pathway to address issues that are important to persons with disabilities with perspectives similar to this study’s participants. For example, any one of the elements of self-employment, wage employment, financial services, social protection, or self-help groups could provide a pathway for beneficiaries to secure material resources. Relating these elements to the findings of this research, however, none of these things are inherently help, although it is possible that they could be approached with a philosophy congruent to help. Accordingly, this study provides the opportunity to think differently about the elements of the CBR matrix.

The main implication of this research for CBR policy, programming, and practice is encouragement not to remain limited to the components and elements of the matrix. One alternative to this is for parties developing specific CBR programs to move slowly, and be willing to engage in activities that are conceived in ways different than their framing in the matrix. Another alternative might be to focus more on developing partnerships with other sectors (including potential helpers), such that CBR programs can serve as facilitators for persons with disabilities and their families to access important resources.

8.3.1.2 Implications for the Convention on the rights of persons with disabilities (CRPD)

The CRPD (UN, 2006) has been developed to ensure the persons with disabilities are able to share rights equal to others (without disabilities), such that there is not discrimination on the basis of disability (UN, 2006, Art. 2). The participants in this research did not prioritize equality and non-discrimination as a concern. Despite having plenty of opportunities through the data generation activities, participants also never spoke about rights or discrimination, according to its definition in Article 2 of the CRPD (UN, 2006). The participants’ concerns were instead related
to basic needs, with inequitable relationships seen as a viable strategy to meet these basic needs. Similar to the critique offered by Meekosha and Soldatic (2011) with respect to the global South in general, it would appear that the CRPD is incongruent to the perspectives of the participants in this research.

The results of this research align better to some aspects of the CRPD than others. Article 28 of the CRPD addresses an “adequate standard of living and social protection” (UN, 2006), a consideration that is aligned with the participants’ expressed needs for material resources. In Article 28 there is a call for “the continuous improvement of living conditions” (UN, 2006), which was also aligned to the concerns and framing of the research participants. The qualifiers that are used in Article 28 that refer to “equal access” and “the realization of this right without discrimination on the basis of disability” (UN, 2006) are not consistent to the concerns and framing of the research participants. The implication of this research on the CRPD is to highlight the importance of the continuous improvement of living conditions.

8.3.1.3 Implications for the Government of Zambia

As I had presented in Chapter 2, Zambia has a strong national government, with most policy of influence being set at the national level and then applied through the provincial and district offices. The prominence of poverty and help in this research are relevant for Government of Zambia policy and services related to disability.

The implication of this study for the Government of Zambia is with respect to the Social Cash Transfer System (SCTS) (MCDMCH, 2013), which I discussed in Section 5.4.5.3. The SCTS is gradually being rolled out nationwide. As a government-supported social safety net of reliable cash payments, the SCTS has the potential to dramatically change the way in which persons with disabilities, like the participants to this research, secure needed material resources. Given the participants’ identification of poverty as their major concern, the SCTS has the potential to improve this dynamic. Conversely, the introduction of a bureaucratic structure has the potential to destabilize social relationships that are currently framed as the main source of support for persons with disabilities. To the extent that the SCTS is implemented, it will be necessary that it is retained to avoid the worst of both worlds: that the community and interpersonal sources of support are undermined, while the official government structure is discontinued.
8.3.1.4 Implications for non-governmental organizations (NGOs)

The participants in this research expressed that they were being neglected by NGOs in Western Zambia. This was despite some awareness that some NGOs did in fact mainstream disability concerns into their programming. The disconnects between the apparent intentions of the NGO strategies and the perceptions of the research participants seemed to be related to priorities. One example of this would be the ways in which accessible toilets at schools (one NGO initiative) would likely benefit persons with disabilities on an ongoing basis, but since this issue was not a priority of the research participants, the participants did not see this strategy as relevant compared to the more pressing priorities of securing material resources.

The implication for NGOs is to continue to mainstream disability concerns into programming more widely, but to also incorporate a parallel track of consideration in which disability is a focus.

8.3.1.5 WHO Disability Action Plan

As described in Sections 1.2.1.1 and 1.2.3.1, the World Health Organization (2015) has oriented its activities around the “WHO Disability Action Plan 2014-2021.” This action plan has three objectives, one of which is rehabilitation (WHO, 2015). Within Objective 2, Rehabilitation, the final of seven actions is the engagement of persons with disabilities. As part of this action, the WHO (2015) suggests that member states “include persons with disabilities and their family members and/or informal caregivers in all aspects of developing and strengthening rehabilitation, habilitation, support and assistance services” (p. 21). Of the seven action items, it is the seventh that is most closely linked to the results of this study.

According to this research, rehabilitation (as described in Section 1.2.3.1) is not the priority of the participants with disabilities and their kin. Therefore, a discussion that is bounded by the limits of rehabilitation is likely off-target with respect to the priorities of persons with disabilities. The associated implication of this study for the WHO Disability Action Plan is that the engagement of persons with disabilities should not begin with the premise that rehabilitation is the solution. It is likely that in many cases, some form of rehabilitation will be among the priorities and needs identified by persons with disabilities; yet this is likely only part of the equation. When member states are following the recommendation of the WHO, they could nest the involvement of persons with disabilities at a higher level, likely into discussions about needs
and priorities (without first identifying a sector). From this foundation, member states could devote resources to disability, and direct to rehabilitation only the portion of these resources that is identified by the engaged persons with disabilities.

8.3.1.6 Professions and their associations

Since I am a member of a rehabilitation profession, it is most straightforward for me to ground the implications of this study in the situation of those professions, but other professions related to disability (special educators, sign language interpreters, among others) could find some parallels to the implications presented here. All professions must recognize that the privilege experienced by professionals can be used to improve the situation of persons with disabilities, but it can also be used to further marginalize persons with disabilities, especially if resources are devoted to strategies that are different from the priorities identified by persons with disabilities themselves.

The findings of this study point to a peripheral role for rehabilitation (as described in Section 1.2.3.1) among the strategies to improve the situation of persons with disabilities. The main implication of this research for rehabilitation professions and their associations is the need to recognize this peripheral role. By recognizing that they are in a peripheral role relative to the needs and priorities of persons with disabilities, rehabilitation professions are in a better position to focus only on the few areas in which they are useful. Alternatively, it is possible for rehabilitation professions to adapt their activities to be better aligned with the targets identified by persons with disabilities themselves. It is not immediately apparent how the rehabilitation professions could engage in strategies such as help, but exploring ways of doing this could help move the rehabilitation professions closer to activities that are important to persons with disabilities.

Professional associations are in a position to take leadership. This leadership could involve the active incorporation of the voices of persons with disabilities at multiple levels. Professional associations can also facilitate a realignment of association activities to match the priorities of persons with disabilities through tools such as journals, conference programming, encouragement of advances in research and training, and explicit statements with respect to professional norms.
8.3.1.7 Implications for individual professionals seeking to improve the situation of persons with disabilities

This study was inspired by my personal experience as an individual with some level of privilege striving to find the most effective ways to improve the situation of persons with disabilities. Whereas the contribution that I could make as a rehabilitation professional seemed obvious in my initial postcolonial encounters, the dynamic revealed itself as increasingly complex with ongoing involvement. In this section I am addressing professionals as individuals, fully recognizing that it is rare that a professional be completely independent. Professional and volunteer commitments often involve employers or at least partners, and a professional must consider the impression of his/her colleagues in order to maintain professional status.

The main implication of this research for individual professionals, at least those who are able to choose to engage in activities to improve the situation of persons with disabilities, is that there is value in suspending one’s faith in what one has to offer, in order to slow down and learn more about the situation that one is trying to address. To the extent that individuals are able to detach themselves from pre-determined solutions and remain open to other possibilities, there is great potential to create strategies that more accurately reflect the complex and diverse realities faced by persons with disabilities globally.

Using the cases of a rehabilitation professional as an example, a given rehabilitation professional who accepts an opportunity to engage with persons with disabilities in a paid or volunteer capacity, could forefront the concern of engaging with persons with disabilities. Many paid and volunteer roles have predetermined expectations and a workload that surpasses what can possibly be accomplished through a full-time commitment. Given these constraints, following this implication could involve some risk for professionals as supervisors and colleagues insist that they just do their job (of maintaining the status quo). It is my hope that in professions that value evidence, the evidence generated as part of this thesis can be used to support professionals who strive to improve the situation of persons with disabilities on the terms of those same persons with disabilities.

8.3.2 Implications for disability theory

It was not the goal of this research to produce an alternative model of disability, but it is possible to relate the findings of the research to the dominant models. The socio-economic phenomenon
of disability that was co-constructed as part of this research shares some similarities to the charitable and social models with some foundational differences. Disability, as co-constructed in this research, was dissimilar to the traditional and medical models.

As a strategy to improve the situation of persons with disabilities, help could be seen as charity. People who believe that resources should be acquired through “dignified means,” such as impersonal economic exchanges or systematic political struggles might be particularly inclined to make an association between help and charity. The corollary to dignified means of resource acquisition could be the undignified means of receiving resources through charity; a distribution mechanism that occurs according to donors who decide independently when, how, or even if, to give to those in need. Help, as articulated through this study, does not work on the same foundational principle. Instead, with help, the helper has a responsibility to share resources while it is the role of the potential recipient to make his, her, or their needs known. In this way of thinking, communicating about a life of suffering is an urgent plea, but not a powerless one. These communications of desperate circumstances are also useful economic resources to be wielded in a society in which compassion can be an expectation. Although it shares some similarities to the charitable model of disability, the socio-economic ways of thinking co-constructed in this research are also inconsistent to this model.

The socio- part of the socio-economic findings of this research share some similarities to the social model of disability. Similar to the original articulation of the social model of disability, participants downplayed the need to fix their impairments and instead located the strategies to improve their situation in concerns of economic participation. Despite this similarity, the participants did not base the strategic responses to their problems in principles of justice but instead on principles of dire material need. In the data generating interactions of this project, equality of persons with and without disabilities was not raised and interest in human rights was not expressed. Instead, the dialogue was focused on immediate problems of resource deprivation, and the solution that those with sufficient resources should share their excess with those who do not have enough.

8.3.3 Implications for research

The insights generated in this inquiry suggest a number of possible lines of inquiry. The following are studies that should be considered:
8.3.3.1 Analysis of diversity within the disability community in Western Zambia

This research produced results that could be encapsulated as single themes. Not only did these themes flow out of a systematic process of analysis, they were also frequent, emphatic and urgent. Nonetheless, in prioritizing these dominant themes, there is a risk of ignoring important differences between persons with disabilities in Western Zambia. Although the exploration of dominant themes in these groups was a good first step, the exploration of differences between persons with disabilities is an important next step.

A future research question to be asked could be: Among persons with disabilities in Western Zambia, how is disability experienced differently according to various aspects of identity and situation?

8.3.3.2 Exploring help as a strategy to improve the situation of persons with disabilities

The participants in this study spoke of help in sufficient detail to assemble a description of this practice, but how would an intentionally-derived practice of help actually work? Research could build upon this study to explore help in more detail, possibly by designing and assessing an intervention. Through this research it could be possible to more clearly establish some considerations about how to make help work, and how to avoid risks that it might entail.

As such, a future research question could be: What are the effects of intentionally engaging in help with a disability group and its members?

The above research question is most appropriate for a context in which disability is likely to be understood as a socio-economic phenomenon (as was the case with this context). In the many contexts in which there could be doubts about the understanding of disability, there is merit in conducting research similar to this study, where a context-specific understanding of disability, and what to do about it, can emerge.

8.3.3.3 Assessing changes that occur with the implementation of the Social Cash Transfer Scheme

As the SCTS is implemented more widely in Zambia, this arrangement could have important implications on the ways that persons with disabilities engage in their communities. In the short-
term there is reason to believe that this involvement would be overwhelmingly positive, as persons with disabilities are able to increase their economic engagement as purchasers of goods and services. In the longer-term there could be positives and negatives, including the possibility that recipients of the SCTS share their resources with their communities (Hansen & Sait, 2011), or that help is undermined.

A future research question could be: What are the community-level effects of the Social Cash Transfer Scheme in small urban centres and rural areas of Zambia?

8.3.3.4 Researching disability beyond the reach of disability groups

I chose to work with disability groups for conscious reasons. The majority of the population of Western Province is rural yet I faced significant challenges in identifying a disability group in a rural area, causing me to deduce that most persons with disabilities in Western Province are not members of a disability group. It is quite likely that the situation of these people would be different than those in groups – for better or worse. Most interestingly, research on disability in communities at-large could reveal a wide variety of understandings regarding disabilities due to the lack of shared experience and collective sense-making that is an inherent element of a group.

A future research question could be: How does the situation of persons with disabilities in Western Zambia who are members of disability groups compare with those who are not?

Research about the comparison of the experience of disability group for people who are, or are not, part of disability groups can have significant contributions to understanding about how disability is understood, advocacy, policy, and even research methods. Although research in Western Zambia would allow a direct comparison with this study, this type of research could also be informative in other settings.

8.4 Limitations

The participants in this study were disability groups and their members, limiting the relevance of these findings to the majority of persons with disabilities in Western Zambia who are not members of a disability group.
The analysis for this study focused on the dominant trends identified in the data and did not include specific analysis of potentially important differences between and within the disability groups.

This research was conducted in an early stage of relationship-building. Although all constructionist research occurs in an interactional dynamic, it is possible that the data generated in this study were limited by the respective positionalities of the researcher and researched due to the early stage of relationship.

8.5 Concluding remarks

In this study, I sought to co-construct of new ways of thinking about disability, and what to do about it, in the context of a postcolonial encounter, involving a North American-trained rehabilitation professional and two disability groups and their members in Western Province, Zambia. The key finding of the study is that disability was conceived in this context as a socio-economic phenomenon. This conception of disability differs from many other conceptions. This contextually-grounded research is important to help inform alternatives to the dominant approaches.

8.6 References


Appendix 1: Research team transcription guide

Transcription conventions
A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia
Version 3 – 16 July 2014
Adapted from Joan Eakin, University of Toronto

Transcription process
An entire recording should be transcribed by a single person for continuity. In the case of exceptionally long documents it is possible to divide the document such that one transcriptionist covers the start to a given time and the next transcriptionist begins from that time. New addition-
After completing the transcription the transcriptionist should review the entire document for quality. End new addition

All transcriptions will be proof-read. The proof-reading will be done by the same person with edits made in track changes. After the proof-reading the transcriptionist will review the edits, discussing with the proof-reader in cases of disagreement.

Document identification
Every transcription document will have a unique title. The complete generic form of the title will be “[Event identifier]_[transcriptionist initials]_tr_[proof-reader initials]_pr_edits_final.doc”. Elements will be added to the title as the transcription evolves. For example, when the initial transcriptionist is working on the document s/he will only use the event identifier and his/her initials and “_tr”. The proof-reader will save the document under a new name, adding his/her initials and “_pr”. When the transcriptionist begins to edit the proof-reading s/he will add “edits”. When the editing process is complete s/he will add “final”.

Documents will have a standard heading, which will be followed by a list of dates: one date for each day the document has been worked on. An example follows:

Focus Group Discussion 1
Site: M
22 April 2014

29 April-transcription
30 April-transcription
3 May-proofread

Int: Shaun
Tr: Akufuna

Timing
The time on the recording should be noted at the end of each transcription session (at the end of the day or before a break) on a new line, in square brackets, after the completion of a given speaker’s speech. An example follows:
P1: And those situations made us very sad.

[13:27]

Int: Why was it that you felt sad?

Language
English should be in normal characters. Silozi (or other Zambian languages) is italicized.

When an interview or focus group discussion is being interpreted, the meaning conveyed by the interviewer or participant may not be accurately interpreted. If so, misinterpreted text appears underlined, and the meaning conveyed by the interpreter is presented in square brackets [ ] in the English version. This means that if the interviewer is speaking English the correct meaning will be displayed as part of the interviewer’s speech; but if a participant is speaking Silozi the corrections will be part of the interpreter’s speech. See the hypothetical example below:

Int: When speaking the interviewer actually said this one thing [the interpreter said this other thing].

Tr-Int: When speaking the interpreter said this other thing.

M6: In speaking Silozi the participant then said this thing.

Tr-M6: In speaking Silozi the participant said that other thing [then said this thing].

New addition-Sometimes speech is not only misinterpreted, but not interpreted in its entirety or at all. This can happen for a variety of reasons, such as when multiple people speak simultaneously during a focus group discussion or when a participant makes a very long comment (where not all can be remembered and processed by the interpreter). In this situation the speech that was not interpreted into English must be identified and translated. If the issue is speech that was not interpreted in its entirety it will be translated prior to the speech of the interpreter. If the speech was not interpreted at all it will be translated immediately after the speaker’s speech. See the hypothetical example below:

K6: This participant said this thing. [This participant said this thing.]

K9: Then at almost the same time this other participant started speaking, talking about his experience in doing this, that, and the other thing. But the participant spoke for a very long time. And then he finally made his conclusion where he talked about this.

Tr-K9: [Then at almost the same time this other participant started speaking, talking about his experience in doing this, that, and the other thing. But the participant spoke for a very long time.] He finally made his conclusion where he talked about this. End new addition

Brackets
If an insertion has to do with the participant, use regular round brackets ( ), if the insertion comes from the transcriptionist or the researcher use square brackets [ ].
Inaudible or unclear
If cannot be heard or is unclear, (after replaying 2x) insert in square brackets: [IA]. If you make a guess put it in square brackets followed by ?? to indicate a guess that the researchers should look at e.g. “He said that I should [IA] [borrow??] the money.”

Uncertainty
If you are uncertain about anything, insert [??] to alert the researchers to check or help interpret.

Grammar/pronunciation
Type as close to the oral original as possible. Do not attempt to ‘clean’, improve or change text. Do not correct grammar or pronunciation.

Where pronunciation is very obvious/audible, write phonetically, eg “He was cheat’n”. but do not attempt this for accented, non-English speech. Some words are commonly “mispronounced” in Western Zambia/Bulozi, but are still easily comprehensible. For example the word “’coz” (for because). These words should be typed as spoken, but noted so that we can make a decision as to whether they should be accepted or clarified. “’Coz” will be accepted as spoken.

If clear to you, put clarification in square parentheses, with a ?: eg “I drug [dragged?] the heavy pallet over with her.”

Acronyms/Shortened words
When an acronym is used, but its meaning is unknown, try to offer a guess/type phonetically e.g., “Rack-wee” is how the acronym RAACWI is pronounced. Insert [??] to indicate that you are unsure, so the researchers can check it. Common acronyms/shortened words that are known to the transcriptionists should be written as acronyms or as pronounced and identified in square brackets. For example “We went to see the DC [District Commissioner]” or “They asked to see my redge [registration card].”

Incomplete sentences, trailing off
Where sentence trails off without completion indicate by (3 dots) “so he sent me the form, and I…Well, I didn’t know, you know.”

Indicating different/change of speakers
Indicate by space and line change when there is a change of speaker (Int = interviewer; Tr = interpreter; M or MF = participant/interviewee, Mongu site; K or KF = participant/interviewee, Kalabo site).

The interpreter’s job is to only change the language of speech, so when speaking she is generally not speaking for herself. For this reason we always identify the person who originally spoke. This will generally mean that the interpreter’s speech is identified as “Tr-int” (when translating for the interviewer) or “Tr-M16” (when speaking for participant M16). In the case where the interpreter is speaking for herself her speech identified according to whom she is addressing. For example, when speaking for herself to “P1” the interpreter would be identified as “Tr-to-P1”. If this occurs directly after the interpreter was interpreting speech, the independent speech is identified as a new speaker. When not in English the interpreter’s speech should be translated to
English using square brackets. In the instance when someone is speaking English and the speech is not translated into Lozi, this should be identified as [not translated].

For focus groups, if you can identify according to the participants’ unique identifiers. If you cannot distinguish, just indicate speaker change or different speaker by starting new paragraph and new heading with the group’s alphabetical code (M or K).

If multiple participants respond simultaneously, indicate them as “M_many” (in the case of Mongu site).

If the interviewer (or another participant, in a focus group) makes short exclamations/utterances (eg ‘uhuh’, ‘right’, ‘go on’, ‘oh my!’), do not change speakers, but insert in text in square brackets eg “I did spot welding with my foot [yeah], twelve thousand times a day [yuy].”

If it is another participant, not the interviewer, indicate this where possible e.g. “They thought I was faking [murmur of agreement – other P].

When a speaker quotes someone else, be sure to distinguish the quote from the speaker’s own speech using quotation marks. Example: the other children would say “Look at the lame one!” and that would make me feel sad.

**Emotion and emphasis**
Record obvious expressions of /indicators of participant emotion within regular parentheses eg “But it fell on the floor (laughs) and broke.”, or “No, I never filed a claim before (!!!)”.
If emphasis significant, surrounds words with asterisks: “No, I *never* filed a claim before (!!!)
If the speaker changes tone insert e.g. (softly) or (loudly).

**Contextual detail**
If noticeable background event or noise, break text to insert eg. (phone rings, he doesn’t answer it), or (laughter from others).

**Pauses**
If 2-3 seconds, indicate pauses “he said maybe I would get better, but (pause) I don’t know”. If it is longer than 2-3 seconds indicate (long pause).
Appendix 2: Blank research assistant performance review sheet

Performance review #__
A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia Research Assistants
[Name]
Day Month 2014

Shaun’s Perspective

Overview:

Strengths:

Weaknesses:

Skills we have worked on:

Skills we have not yet worked on:

[RA]’s Perspective

Overview:

Strengths:

Weaknesses:

Skills we have worked on:

Skills we have not yet worked on:
Appendix 3: Letter to confirm employment as a research assistant

22 August 2014

TO WHOM IT MAY CONCERN
Re: Patrah Likonge Kapolesa

Dear Sir/Madam,

The purpose of this letter is to confirm that Ms. Patrah Likonge Kapolesa worked in the position of research assistant (RA) in the “A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia” study over the course of 22 weeks, completing approximately 840 hours of work.

In this role Ms. Patrah Likonge Kapolesa completed the following tasks:
- Translation of written documents (English to Lozi),
- Organization and planning of study activities,
- Liaising with local organizations,
- Transcription of audio recordings,
- Interpretation of interviews and focus group discussions (English and Lozi or Mbunda),
- Proofreading and editing of documents, and
- Supervision of new employees.

In completing her duties Ms. Patrah Likonge Kapolesa performed consistently at a very high level, producing work that was reliably of high quality. Furthermore, she was devoted to the successful completion of this work, and showed exceptional initiative through the modification of her schedule the proposing of new ideas.

Please do not hesitate to contact me to discuss any further elements related to Ms. Patrah Likonge Kapolesa’s involvement in this project.

Sincerely,

Shaun Cleaver, PT, MSc, PhD (student)

Doctoral Student
Graduate Department of Rehabilitation Science
University of Toronto (Canada)

Affiliate,
The ZABART Project, Social Science Team
PO Box 50697, University of Zambia Ridgeway Campus,
Ridgeway, Lusaka, Zambia
Email addresses: shaun.cleaver@mail.utoronto.ca (until end-2015); shauncleaver@gmail.com
Appendix 4: Introductory letter to disability groups

[Date of letter]

[Name of disability community]
[Address of disability community]

RE: A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia

Dear [name of leader of disability community, if available; Sir/Madam if contact name not available],

I am a student from the University of Toronto, in Canada, also affiliated with the ZAMBART Project in Lusaka. As part of my program I need to conduct a research study. For this research I have decided study activities, services, and initiatives by or for persons with disabilities in the Western Province. I am doing this study in partnership with the Zambian Federation Disability Organisations (ZAFOD).

I recently heard about [insert name of disability community] from the provincial office of the Zambian Agency for Persons with Disabilities (ZAPD) [or from the source specified here]. I would like to talk to you about the possibility of your group also participating in this study as a community partner.

The plan for this study is to have community partners participate in two focus groups about activities, services, and initiatives by and for persons with disabilities. Focus groups are activities where we will come together to discuss some questions that I will ask. Some members of your group can also participate in a private interview to discuss activities, services, and initiatives for persons with disabilities, if they so choose. I will lead all of these activities, but will do so with the assistance of a research assistant and translator. As participants you will be able to decide if you want these activities to occur in English, in Lozi, or in another language of your choice (including the possibility of a sign language, such as Zambian Sign Language). As part of the study I would also like to visit the members of your group in their home villages or compounds so that I can have a better idea of the things that are important to you.

Participating in this study will not cause any immediate changes to the activities, services and initiatives that [insert name of disability community] or your members receive. We hope that by doing this research we can improve activities, services, and initiatives for persons with disabilities in the Western Province, but if this happens it could take a long time to happen.

It is the choice of [name of disability community] and its members to participate in this study or not. If you decide to participate we will create a written agreement so that we all better
understand what to expect, but even with this you are still able to change your mind and stop participating. Even if the group decides that it wants to participate in the study I will need to speak with each individual member of the group to be sure that they want to participate. It is possible for the group to participate but some members to decide that they do not want to.

I hope that we are able to meet at least one more time to discuss this study in more detail. You are welcome to call, text, or send me a missed call at the number above and I can return your call. This way you can contact me to ask me any questions you may have and to organize a time to meet again. If I do not hear from you I will contact you by telephone, or visit you in-person, in one week’s time. Thank you kindly for your contribution.

Best regards,

Shaun Cleaver
Doctoral Student,
Graduate Department of Rehabilitation Science,
University of Toronto (Canada)

Affiliate,
The ZABART Project, Social Science Team
Ridgeway, Lusaka, Zambia

Local address:
ZAFOD Provincial Office
Provincial Education Building,
Boma, Mongu, Zambia
Mobile phone: +260 977 140 241
PARTICIPANT INFORMATION SHEET
For the members of disability communities

TITLE OF RESEARCH:

A SEARCH FOR STRATEGIES TO REDRESS THE DISADVANTAGE OF DISABILITY IN WESTERN ZAMBIA.

PURPOSE OF THE STUDY:

My name is Shaun Cleaver, and I am a PhD student at the University of Toronto (Canada) who is affiliated with the ZAMBART Project in Lusaka. My work is funded by the Canadian Institutes of Health Research and the W. Garfield Weston Foundation. I am doing this work together with Patrah, Akufuna, Aongola and Malambo who are here to assist by translating from Zambian languages to English, while also helping with some other tasks.

We are doing research where we wish to create new ways of thinking about disability, and ways to counter the disadvantage of disability, through a PhD student project with disability communities and their members in Western Province. In this research we will work together with you and your community in order to create better information about the activities, services, and initiatives that will help you live better. We will prepare this information and give it to you so that you can use it to improve the activities, services, and initiatives that are available to you. Your disability community has agreed to participate in this research.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT:

This study takes place in various parts over a period of approximately six months. In order to collect information for the study we will do three things:

1) Focus group discussions with the disability community,
2) Individual interviews with members of the disability community, and
3) Participant observation with the disability community and/or its members.

Focus group discussions are meetings that we will do together with all of the members of your community who choose to participate. We will do two focus group discussions; one very early in the project and another about one month later. In these focus group discussions we will talk about disabilities and the things that can be done to counter the disadvantage of disability (such as activities, services, and initiatives). The focus group discussions will be audio recorded if all of the participants agree to this. We will hold these focus group discussions at times and in locations that are convenient for your community. We will help to cover the cost for your travel to the focus group discussions and provide a shared meal for all participants.

Individual interviews are conversations that we will have with you at a time and location that is convenient. During the individual interview we will also be talking about disabilities and what to do about them, but we will have more time to talk, since it will just be the two of us instead of an
entire group of people together. The individual interviews will be audio recorded, if you give your permission, and should last approximately 30 minutes.

Participant observation means that I will spend time together with you so that I can see what daily life and special events are like for you. I will likely conduct the participant observation before and after the focus groups discussions and the individual interviews, although we could arrange another time if you would prefer that. During the participant observation we can visit any locations that you would like to show me, such as the main places where you spend your days. During this time I will be mostly watching and listening, but I may chat with other people too, if that is acceptable to them.

We will strive to account for all of the particular ways that you, or other members of your community, function. It is for this reason that when we researchers will travel to meet the community in its usual meeting places when we meet as a group, or to a location of your choice when we just meet with you. We will use the language of your choice when we collect information, and this choice can be a sign language. We will work together to address any other aspect that functioning that is important for you to participate fully in this study.

CONFIDENTIALITY:

All of the information that we collect for this study will be confidential. Paper information will be securely stored in locked cabinets inside locked rooms. Information stored on computers will be encrypted. The information that people give separated from their names. During the focus group discussions we will ask you and all other participants to please keep the discussion confidential (that is to say, please do not tell other people what we talked about). Unfortunately, we cannot guarantee that everyone will maintain confidentiality.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Your participation in the research is voluntary. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you no longer wish to participate in this research, you may do so with no negative consequences. We can also remove the information that you provide for this study if you ask us to do so.

RISKS AND BENEFITS:

Talking about social and personal limitations may make you feel sad or embarrassed. We have worked with disability communities in the past and are familiar with the issues that people report. Should it happen that someone feels sad or embarrassed we will address these feelings, even stopping the focus group discussions or interviews if necessary. We will restart only if that person grants us permission to resume. Should the feelings of sadness or embarrassment persist we will contact the local coordinator for the Zambian Federation of Disability Organisations (ZAFOD) to help connect the person with helpful services.

There is also a risk that some organisations that provide activities or services are angry to see any information that is negative about their programs. We think that it is important to tell these organisations about the ways that their programs are good or are insufficient and see this study as a way to do this without having to name the individuals who identify the problems. As the
study’s researchers we will communicate with those organisations through written reports and presentations. We will name your disability community in those reports and presentations but will never mention which person said what things. It is for this reason that we are asking that everyone who participates in the focus group discussions not talk to other people what we spoke about afterwards. Unfortunately, we cannot guarantee that everyone will do this.

This study could lead to some possible benefits for you or your community. The possible benefits are primarily related to the feedback and action components of the study and include:

• A comprehensive written listing of activities and services that are available to you.
• The sharing of initiatives between people so that you can all know of different ways to improve your lives.
• A detailed analysis of activities, services, and initiatives in order to allow you and the other people in your community to pursue the development of these programs independently or with partners.
• Experience in participating in the research process in order to better understand how formal research evidence is viewed and used by decision-makers.

The study is a student research project to increase understanding and will not include any direct material benefits such as money or food rations.

CONTACTS FOR QUESTIONS (Names, addresses, and phone numbers of the following):

1. **Principal Investigator**, Shaun Cleaver, University of Toronto, c/o ZAFOD Provincial Office Provincial Education Building, Boma, Mongu, Zambia; Cell No: +260 977 140 241 / +260 962 647 889

2. **Chairperson**, Humanities and Social Sciences, Research Ethics Committee, University of Zambia. Professor Augustus Kapungwe, Telephone: +260 211 290 258

3. **The Director**, Directorate of Research and Graduate Studies, University of Zambia. Telephone: +260 211 290 258
Appendix 6: Consent form – English version

CONSENT FORM
For the members of disability communities

TITLE OF RESEARCH: A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia

Please review the study Participant Information Sheet prior to completing this consent form.

1. Make sure that you read the Participant Information Sheet carefully, or that it has been explained to you to your satisfaction.

2. Your permission is required if tape or audio recording is being used.

3. Your participation in this research is voluntary, i.e. you do not have to participate if you do not wish to.

4. Refusal to take part will involve no penalty or loss of services to which you are otherwise entitled.

5. If you decide to take part, you are still free to withdraw at any time without penalty or loss of services and without giving a reason for your withdrawal.

6. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.

7. The information collected in the focus group discussions, interviews and participant observation will be kept strictly confidential. We will ask all of the participants in the focus group discussions to also maintain confidentiality, but we as researchers cannot assure that they will.

8. If you choose to participate in this research study, your signed consent is required below before we begin the research activities such as focus group discussions, interviews or participant observation.

-----------------------------------------------------------------------------------------------------------------------------

VOLUNTARY CONSENT

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time, and to choose not to answer particular questions that are asked in the study.

My signature below says that I am willing to participate in this research:

Participant’s name (Printed): ..................................................................................................................................................

Participant’s signature: ................................................... Consent Date: ..........................................................

Researcher Conducting Informed Consent (Printed) .................................................................

Signature of Researcher: ................................................. Date: ..........................................................

Signature of Witness (if necessary): ......................... Date: ..........................................................
Appendix 7: Focus Group Discussion Guide – Round 1

Community identifier ____

A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia
Focus Group Discussion Guide - Round 1

Focus group activity 1: Shaun leads the discussion based on the questions below, while making explicit note of activities, services, and initiatives as they emerge in discussion.

1. Please tell me about how you might experience life differently as persons with disabilities?

2. How does having a disability make your lives better or easier than people you know who do not have disabilities?

3. How does having a disability make your lives worse or harder people you know who do not have disabilities?

4. What do you do to make your lives better or make them easier?

5. What do other people do with or for you to make your lives better or make them easier?
Appendix 8: Individual Interview Guide

Participant no. ____

A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia
Semi-structured Interview Guide for Individual Members of Disability Communities

1) Do you consider yourself to have a disability?

1a) *If not*, why are you connected to the disability movement?

1b) *If the reason is because of a family member, such as a child, with a disability*, why do you consider that person to have a disability?

2) Tell me about your disability [your family member’s disability] and how it affects your [her/his] life.

3) What do you do to make your life [your family member’s life] better or easier?

4) What do other people do with or for you to make your life [your family member’s life] better or easier?
Appendix 9: Focus Group Discussion Guide – Round 2

Community identifier ____

A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia
Focus Group Discussion Guide - Round 2

Focus group activity 1: Shaun presents all the activities, services, and initiatives (i.e., strategies) gathered through the first focus group and identified through the environmental scan. These strategies are presented as a list. Focus group participants are invited to add strategies to the list.

Focus group activity 2: Shaun continues the discussion according to the strategies from the list.

A) Let us talk about [the first strategy on the list]; does anyone here use this strategy?

   A1) If so, tell me about how this meets your needs? Are there other things you would like to say about [the first strategy]?

   A2) If not, why do you not use this strategy? Have you heard of anyone who does use it? What have you heard about [this strategy]?

[Repeat for as many strategies as the group wants to discuss]

Focus group activity 3: Shaun leads the discussion while making reference back to the strategies on the list as potentially related elements emerge in the discussion.

B) You mentioned some good things about your lives [in the absence of strategies, or because of them], how can we create more good things like these ones?

C) You mentioned that there are some bad things happening [despite strategies, or because of their absence], how can we change those bad things?
## Appendix 10: Initial code book

<table>
<thead>
<tr>
<th>Code, question</th>
<th>Source</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What do participants mention as an existing activity, service, or initiative?</td>
<td>Deductively derived from research question 1 (RQ1): “What is the extent, range, and nature of activities, services, and initiatives available to urban and remote disability communities and their members?”</td>
<td><strong>Tr-KE2:</strong> [The white man] even wrote the people who were suffering and people who were living in poverty their names and their places [unhu]. In each place he asked for one person who is educated who will be writing the report maybe like writing the medicine... and writing the names of people who were living in poverty, taking the names for him. Now when he did that job he got the names and wrote them in the book. Now he gave the order to say “These people now you should build houses for them these people who do not have [IA]”. A house and a kitchen and a fence.</td>
</tr>
</tbody>
</table>
| 2. How do participants describe life with a disability?                           | Deductively derived from RQ2: “What understandings of disability emerge from urban and remote disability communities and their members, referring to their disabilities in particular and disability in general?” This code focuses on individual experience. | **Int:** So as a mother with a disability did you ever have problems with (pause) going to do things that other mothers do with their children?  
**Tr-M10:** Yes, there is a problem.  
**Int:** Mmmmm, can you tell me about that problem?  
**Tr-M10:** It’s very hard for you, a parent who is disabled, to take care of your child and to make sure that your child looks like other people’s children who are not disabled.  
**Int:** Yeah. Can you tell me why that’s a case?  
(Long pause)  
**Translator speaking to Int:** Maybe to finish, she said “because it’s hard for me to find money.” |
<p>| 2a. How do participants describe disability identity?                             | Inductively derived from the presence of quotes the talk about the collective categorization of disability, referring more to the ‘disability in general’ aspect of RQ2.                                      | <strong>From fieldnote in Kalabo:</strong> Debate ensued about the disability status of one person. According to the committee members “he does not have a disability; he only has leprosy.” In this manner of speaking, they might have been saying that the person had ‘a diagnosis of leprosy that was successfully treated without any residual impairment’, but they could have been talking about something else. In the interest of simply letting them decide, I did not intervene. |</p>
<table>
<thead>
<tr>
<th>2b. How do participants describe economic life in ways that run counter to my understandings of economics?</th>
<th>Inductively derived from a series of focus group discussion quotes that I found challenging to understand. I found these quotes remarkable in that they a) all related to money, and b) presented terms of social interaction that did not make sense to me. I see this as a subset of RQ2.</th>
<th><strong>Int:</strong> So if I was to make that suggestion [of starting a loan program] people would be asking me and they will ask you “why is [the group in this town] different than these other groups [that all defaulted on their loans]?” <strong>Tr-KE2:</strong> I don’t know. With the money now, I don’t know, it depends with how many you are in the group because the same money you need to pay with an interest. Now the same interest that’s the same interest that can help the business or the job to grow. <strong>Int:</strong> Oh, ok. Well in that case you are thinking about something different than am thinking about. <strong>Tr-KE2:</strong> Ah what I mean myself is the money because if you are given money, the same money that you are given, you use the same money so that you can earn an interest on top.</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. What things do people say about existing activities, services, and initiatives?</td>
<td>Deductively derived from RQ3: “What are the perspectives of urban and remote disability communities and their members on existing activities, services, and initiatives?”</td>
<td><strong>Int:</strong> Ummm, so does that... so what I would like to know, is when you go to the clinic, are those [accessibility adaptations] there or are they not there? <strong>Tr-many:</strong> They are not there. <strong>Int:</strong> They are not there. Ok. And what are the clinics that you go to that you find that those things are not there? <strong>Tr-m7:</strong> Even the urban clinic also, which is near Lewanika. They just built for ordinary persons they did not specify that “this side is for persons with disability and then this side is for ordinary people.”</td>
</tr>
<tr>
<td>4. What things do people say about the future activities, services, and initiatives that they want?</td>
<td>Deductively derived from RQ4: “What aspirations do urban and remote disability communities and their members express regarding potential future activities, services, and initiatives?”</td>
<td><strong>Tr-m5:</strong> Like for me, I am an electronic repair [IA], and I need money which can help me improve my business. Now if those people help me with a loan, we can agree on how I should be returning the money, and I can be returning the money. Because by then, I can be able to buy even other materials I can put on my stand and by doing that, it can help me have more money.</td>
</tr>
<tr>
<td>4a. What situations do people identify as bad and needing to be addressed?</td>
<td>Inductively derived from statements that seemed to relate closely to RQ4, but were not quite right in that they are expressed as problems instead of aspirations or propositions.</td>
<td><strong>Tr-m4</strong>: The water we drink, we find it difficult. We can’t get running water to our places. (Long pause) But because water is life or it’s the one which can make someone to live, we need it every day. But we fail to find it easily or to connect it easily. The water we drink, we draw it from those who have got taps, and those people they need money from us who are disabled. We find it very difficult in our life.</td>
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</table>
| Admin1. Is this a situation where the translation seems inaccurate? | Inductively derived from reading transcripts where there seemed to be inaccurate translation. | **Tr-KE9**: I had such plans some time back. I realized maybe keeping them, sometimes those, the owner, might come at any time “no give us our shoes.” Maybe it can bring some chaos of some kind.  
**Int**: Ok, bring some cows? (Sorry) He can bring some cows (Yes) of some kind.  
**Tr2**: Aah-ah, not cows, problems.  
**Tr-to-Int**: Chaos [pronounced “cows”]... problems not cows. I mean problems. |
Appendix 11: Early emerging ideas – in written form

Shaun Cleaver Doctoral Dissertation
Manuscript Development Brief

#1.1 – The primacy of material resources as an issue for Zambians with disabilities in Western Province
31 March 2015

Alternative titles:
1) ‘All roads lead to material resources’: The priority of groups of Zambians with disabilities and their members as co-constructed in a low-income research setting

2) “That is what I am saying, everything depends on money”: The priority of groups of Zambians with disabilities and their members as co-constructed in a low-income research setting

Background
During the data generation phase of this dissertation research project I had the strong sense that our interactions were dominated by concerns about money or material resources (i.e., food, housing, equipment). Through further review of these data I can now see that this sense was indeed the most important and extensively discussed topic in our data generation activities.

The main message
In reviewing the total sum of data generated during those activities I am confident that we would determine that it was this categorical topic that occupied the most time and required the most words. I mention this phenomenon in order to forget it: in this qualitative constructivist research I believe that the argument that I am trying to make is that it was this topic that was the most adamantly emphasized, or had the greatest importance or the highest value. If this is the conclusion of the paper, then I consider my challenge to be articulating the argument that this was indeed so.

The substance
For better or worse, I am not seeing the available data as clearly and easily convincing of the above argument, with the exception of a few “perfect” quotes like the one presented in title #2 (from a rural focus group discussion). Arguments that I do see better supported through these data include:
1) That most other topics were discussed with little interest or energy until either I a) changed the subject, or b) we began to discuss material resources, and

2) The ways in which material resources were presented as compelling.

The primacy of material resources: compelling, distracting, both, or something else?
To get straight to my overarching impression, although I suspect that all of the above are true, what jumps out at me most clearly is the discordance between the accounts of the participants and other sources of evidence. With this consideration, the star of the show then becomes the presentation of the message and not the message itself. This is interesting; but also problematic. Here I outline the
presentations that I am seeing at this stage in the analytic process, before discussing some of the problems with the entire framing.

**How participants present the need for material resources**

1) By presenting themselves as able (i.e., “resourceful”) or unable (i.e., “helpless”). In some instances the individual narrative delivered by a participant contains only reference to ability or inability, but many include a combination of both. On the whole, inability was presented more often (and more adamantly?) than was ability.

2) By presenting the abundance of resources in other places and at other times (with a concordant emphasis that here and now there is an insufficient supply).

3) By presenting existing distribution mechanisms as flawed and insufficient through accounts that ranged in specificity from highly detailed to vague and abstract. These mechanisms were commonly presented as ineffectual (e.g., the impossibility of successful collective action among PWDs) and/or driven by other concerns (e.g., corruption), with the results being insufficient distributions and broken promises.

**Yes, but...**

I am striving to operate from a participatory research frame, yet the explanation I have provided above is predominantly the opposite of participation: instead of amplifying my participants’ “voices” I could be seen as delegitimizing their concerns by questioning (and discrediting?) their accounts.

The issue above does not completely negate the value of the analysis to date, but it does complicate things. I can see at least a few “ways out,” but at this stage am unsure of the relative merits of these options. Some possibilities include:

1) Recognizing the participants’ accounts as being legitimate due to the energy they required to construct the effectiveness of them at garnering my attention. Even if these accounts conflict with other facts (e.g., the existence of abundant services elsewhere), they still have significant merit.

2) The deployment of these presentations is driven by other sociological concerns, such as the relatively recent transition to the global capitalist economy (driven by growth and consumption, coupled with seemingly endless opportunities yet extensive and increasing inequality), and more “traditional” socio-economic values of production, consumption, sharing and intentional wasting of perishable resources for which there were no storage mechanisms (refer to work of Max Gluckman about the traditional Lozi economy).

**The way forward**

I have written this brief for Stephanie due to our combined involvement in identifying this as a hot topic to be pursued. I would like to review my thinking to date on the idea before delving more deeply into a) data, b) writing, and/or c) literature.

I suspect that an opinion from Ginny (if the findings are set against “traditional” and or “globalizing” forces), or Lilian (if the prime concern is framing the work such that it can be aligned with the data but still supportive of the participants) early in this process could be helpful.
In parallel to strengthening the framework I propose that the potential journals be considered (*Disability and Society* comes to mind, but I am generally unfamiliar with the content and format of that journal). I also propose that this manuscript idea be used to form the template as to how a) the feedback of all PAC members can be incorporated into the evolving work, and b) to establish authorship.
Appendix 12: Early emerging ideas – in diagram form
Appendix 13: Evolution of manuscript ideas into Chapters 4 and 5
Appendix 14: University of Toronto, Health Sciences Research Ethics Board Approval

PROTOCOL REFERENCE # 29653
January 29, 2014

Dr. Stephanie Nixon and Dr. Helene Połatajko
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Mr. Shaun Cleaver
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Stephanie Nixon, Dr. Helene Połatajko and Mr. Shaun Cleaver,

Re: Your research protocol entitled, “A search for strategies to redress the disadvantage of disability in Western Zambia”

ETHICS APPROVAL

Original Approval Date: January 29, 2014
Expiry Date: January 28, 2015
Continuing Review Level: 2

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol, for a period of one year. Ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Elizabeth Peter, Ph.D.  Daniel Gyewu
REB Chair  REB Manager
Appendix 15: University of Zambia Research Ethics Committee Approval

THE UNIVERSITY OF ZAMBIA
DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

Telephone: +260-211-290258/291777
Fax: +260-1-290265/253952
E-mail: drrc@unza.zm
IRB: 00006464
IORG: 00005376
P O Box 32379
Lusaka, Zambia
Your Ref:
Our Ref:

15th January 2014

Mr. Shaun Cleaver
ZAMBART Project
Ridgeway Campus
P O Box 50027
LUSAKA

Dear Mr. Cleaver

APPLICATION FOR ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for your proposed study entitled “A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia”.

In view of the fact that there are no issues involved that raise ethical concerns, you are hereby given ethical clearance to proceed with your project.

Please note that you are expected to submit to the Secretariat a Progress Report and a copy of the full report on completion of the project.

Finally, and more importantly, take note that notwithstanding ethical clearance given by the HSSREC, you must also obtain express authority from the Permanent Secretary Ministry of Health, before conducting your research. The address is: Permanent Secretary, Ministry of Health, Ndeke House, P O Box 30205, Lusaka. Tel:260-211-2530406; Fax +260-211-253344.

Yours sincerely

Dr. Augustus Kapungwe

CHAIRPERSON, HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc  Director, Directorate of Research and Graduate Studies
Assistant Director, Directorate of Research and Graduate Studies
Assistant Registrar (Research), Directorate of Research and Graduate Studies
Appendix 16: Zambia Ministry of Health Approval

17th February, 2014

Mr Shaun Cleaver
University of Toronto/affiliate
The ZAMBART Project
Ridgeway
LUSAKA.

Dear Mr Claver,

Re: Request for Authority to Conduct Research

The Ministry of Health is in receipt of your request for authority to conduct a study entitled "A Search for Strategies to Redress the Disadvantage of Disability in Western Zambia." I wish to inform you that following submission of your request to my Ministry, our review of the same and in view of the ethical clearance, my Ministry has granted you authority to carry out the above mentioned exercise on condition that:

1. The relevant Provincial and District Directors of Health where the study is being conducted are fully appraised;
2. Progress updates are provided to MoH quarterly from the date of commencement of the study;
3. The final study report is cleared by the MoH before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the MoH, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

[Signature]
Permanent Secretary
MINISTRY OF HEALTH
Cc: Provincial Medical Officer - Western