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"All of the problems of poverty are brought because of being disabled": Exploring the particularities of poverty experienced by Zambians with disabilities in Western Province.

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Abstract:

Background:

In qualitative research about the lived experience of disability in Western Province in Zambia, persons with disabilities spoke frequently and emphatically about poverty. This is unsurprising as this province is consistently identified as having high levels of poverty. However, in the participants' narratives, it was striking that poverty was often presented as a condition experienced exclusively by persons with disabilities. This finding creates a dilemma for efforts to address poverty among persons with disabilities: should their poverty be thought of as distinct from, or similar to, the poverty experienced by persons without disabilities?

Purpose:

To explore how these people with disabilities discussed poverty, with particular attention to narratives that are particular to persons with disabilities and those that could be common to persons with and without disabilities.

Methods:

This study was a secondary analysis of data generated for a constructionist qualitative research project. The participants were 81 persons with diverse forms of disability from an urban and a rural community in Western Province. Data were generated through eight focus group discussions and 39 interviews. In the primary analysis, emergent nodes were derived from the transcribed data using NVivo 10. Nodes related to poverty were reviewed through the secondary data analysis to address the study purpose.

Results:

The secondary analysis identified multiple aspects of the experience of poverty that were particular to the situation of these persons with disabilities. These aspects included those where a disability reduced the ability to acquire resources through loans, income, or physical tasks. There were also increased expenses related to disability, such as paying for things that others *just do*, or the costs to mothers with disabilities to raising children after being abandoned by their husbands. Other aspects of the experience of poverty were not clearly traced to disability. Examples of these included restricted access to starter capital for small business ventures and cost barriers to education and skills training.

Conclusions:

This study helps to inform a "twin-track approach" to poverty alleviation and development. The aspects of the poverty experience that are particular to persons with disabilities are potential targets for disability-specific action. Other aspects could be common to the experience of poverty for persons with and without disabilities and therefore opportunities for persons with disabilities to seek inclusion into the mainstream movements.

"All of the problems of poverty are brought because of being disabled": Exploring the particularities of poverty experienced by Zambians with disabilities in Western Province.

Background:

Throughout the world, disability is considered to be a situation of disadvantage.¹ Despite the general phenomenon of disadvantage, disability is also understood differently according to culture and context.² In research that we conducted³ to explore the meaning of disability in Zambia's Western Province, persons with disabilities spoke frequently and emphatically about poverty.⁴

It should be noted that the concern for poverty emerged within the research project; the study had not been designed to focus on this issue. Nonetheless, this finding was not surprising given that the links between poverty and disability are well-established.⁵ As generally understood, poverty is both a cause and consequence of disability. Persons with disabilities are more likely to be poor because it is more difficult for them to earn an income and because they face higher costs of living to pay for equipment and support.⁶ People who live in poverty are more likely to experience disability due to increased exposure to disabiling conditions, barriers to accessing treatment in the case of injuries or illness, and the inability to mitigate the effects of negative changes to their bodies' structure or function.

¹ World Health Organization (WHO) & World Bank. (2011). *World report on disability*. Geneva: World Health Organization.

² Groce, N.E. (1999). General Issues in Research on Local Concepts and Beliefs about Disability. In: H. Holzer, A. Vreede, G. Weigt (editors). *Disability in different cultures: Reflections on local concepts*, (pp. 285-296). Piscataway, NJ, USA: Transaction Publishers.

³ Cleaver, S. (2016). Postcolonial Encounters with Disability: Exploring Disability and Ways Forward Together with Persons with Disabilities in Western Zambia (*Doctoral dissertation, University of Toronto*).

⁴ See Chapter 4 of Cleaver (2016), pp.69-95.

⁵ Grech, S. (2016). Disability and poverty: Complex interactions and critical reframings. In: S. Grech & K. Soldatic (eds.), *Disability in the Global South*, (pp. 217-235). Cham, Switzerland: Springer International.; Yeo, R. & Moore K. (2003) Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development*, 31(3), 571-90.

⁶ Mitra, S., Palmer, M., Kim, H., Mont, D., & Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and health journal*, 10(4):475-484.

One poverty-relating finding from the research with persons with disabilities in Western Province was surprising: the participants often presented poverty as a condition experienced *exclusively* by persons with disabilities.⁷ Since that research was not designed to focus on poverty, there was no attempt to quantify poverty in any way, neither among the study participants with disabilities, nor their neighbours without disabilities. Although poverty was not quantified in this research, it was qualified through extensive analysis of the participants' accounts: participants spoke of poverty as the combination of a lack of material resources and a life of suffering.⁸

The participants with disabilities' accounts of the exclusivity of poverty and disability conflicts with common understandings of disability and poverty for two reasons. The first reason is conceptual: although both poverty and disability are understood in complex ways, there is nothing in the definition of either that requires the other. When disability is presented relative to poverty, these are typically presented as distinct concepts, even though they might be related in a vicious cycle⁹ or as overlapping circles.¹⁰ The second reason is quantifiable: the percentage of the population living in poverty in Western Province is higher than the percentage of the population living with disabilities. Poverty and extreme poverty are quantified in Zambia's Census of Population and Housing¹¹ using Living Conditions Monitoring Surveys (LCMS). According to the Census, Western Province consistently has the highest levels of poverty and extreme poverty (80.4% and 64.0% in 2010).¹² Simultaneously, Western is also among the provinces with the highest levels of disability prevalence, conservatively estimated at 2.9% in

⁷ These results are presented most specifically in Cleaver (2016), Section 4.3.2.2, pp 80-2.

⁸ See Cleaver (2016), Sections 4.3.2 and 4.3.3, pp 77-86.

⁹ The relationship of disability and poverty is most commonly presented as a "vicious cycle," and typically referenced back to Yeo & Moore (2003).

¹⁰ Yeo, R. (2005). *Disability, poverty and the new development agenda*. Disability Knowledge and Research Programme. In this paper, Rebecca Yeo reflects back on the components of the vicious cycle analogy with new thinking, proposing that "perhaps the relationship would be better described as interlocking circles" (p 20). ¹¹ Central Statistical Office (CSO). (2012). *Zambia 2010 Census of population and housing, National analytical report*. Lusaka: Author. Retrieved July 14, 2017 from http://catalog.ihsn.org/index.php/catalog/4124 ¹² See CSO (2012), Table 1.1, p 2.

the 2010 Census,¹³ and more comprehensively estimated at 22% in a study focused on identifying persons with disabilities.¹⁴ Even after accounting for some variability in terms of the meanings of poverty and disability, there is reason to believe that poverty, as conventionally understood, is not exclusively a disability issue in Western Province.

The disconnect between the participants' accounts of poverty and disability, as compared to more general understandings of these concepts, brings forth multiple questions. Among these questions we might ask: Upon closer examination, are persons with disabilities drawing upon a different concept of poverty, one that is exclusive to disability?

Although answering the above question would make a useful contribution to social science literature, there are also questions that are immediately practical. Moving forward from this research project, we have the opportunity to build an ongoing participatory action research arrangement with the participants with disabilities in Western Province. Key facets of this arrangement are shared ownership of future research projects (i.e., participation) and ongoing engagement in issues that are meaningful to the community (i.e., action). According to the findings of the initial research project, poverty is a major concern to the participants with disabilities, and therefore, a potentially important issue for collective action between researchers and community members. However, if we are to pursue collective action on poverty with persons with disabilities, should we be acting towards a particular type of poverty? Should we be looking to connect with wider poverty alleviation movements (with people who are not disabled)? Instead, are there reasons why we should explicitly detach ourselves from those wider movements, focusing all energies toward the poverty of persons with disabilities?

Purpose:

¹³ See CSO (2012), Chapter 11.

¹⁴ See Eide & Loeb (2006), Appendix 2, p 181.

Considering the surprising finding that poverty was presented as being exclusive to disability in the original study, we seek a deeper understanding about the ways in which the phenomena of disability and poverty were related to one another. Accordingly, the purpose of this paper is to explore how these people with disabilities discussed poverty, with particular attention to narratives that are particular to persons with disabilities and those that could be common across people with and without disabilities.

Methods:

This study was a secondary analysis of data generated for a constructionist qualitative research project that was conducted as a doctoral dissertation.¹⁵ The purpose of the primary research was to explore meanings of disability; the methods of the project are described indetail in the dissertation.¹⁶ Here, we restrict our presentation of methods to those details which are most relevant to the secondary analysis.

The participants in this study were 81 persons with disabilities from two communities (one urban; one rural) in Western Province. Recruitment was limited to persons with disabilities to fulfill a principle of the disability movement: that persons with disabilities be involved with matters that concern them.¹⁷ Accordingly, the original project was designed to focus upon the perspectives of persons with disabilities with respect to their own situation. Data were generated through eight focus group discussions and 39 interviews. In the primary analysis, emergent nodes were derived from the transcribed data using NVivo 10. Nodes related to the participants' accounts of their economic situation were reviewed through the secondary data analysis. In reviewing these nodes, we searched for instances where participants referenced causes or

¹⁵ Cleaver (2016).

¹⁶ See Cleaver (2016), Chapter 3, pp 49-68, or Section 4.2, pp 71-4.

¹⁷ Charlton, J.I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.

consequences of poverty. We organized these references to poverty into instances that were particular to life with a disability and those that were not. Recognizing that disability can be understood in multiple ways,¹⁸ we considered disability to be a functional limitation that occurs in the interaction between individuals' impairments and the environments in which individuals live.¹⁹ We therefore considered an instance to be particular to life with a disability if there was a direct and specific relationship between poverty and a functional limitation.

Results:

The secondary analysis identified instances where participants referenced the causes or consequences of poverty (understood to be a combination of a lack of material resources and a life of suffering). Many of these instances could be specifically and directly linked to disability, understood as a functional limitation, while multiple other instances could not be linked specifically or directly.

References of poverty specifically linked with disability included instances where persons with disabilities faced barriers accessing material resources and instances of persons with disabilities incurring additional expenses as compared to persons without disabilities. An overview of the barriers to accessing material resources and of the additional expenses is presented in Figure 1.

[Insert Figure 1 about here]

Participants reported barriers in accessing resources in relation to acquiring money, specifically through difficulties accessing employment and credit. With respect to barriers to

 ¹⁸ Masala, C. & Petretto, D.R. (2008). Disablement to enablement: Conceptual models of disability in the 20th century. *Disability and Rehabilitation*, 30(17): 1233-44; See also, Cleaver (2016), Section 1.2.2, pp. 11-17.
 ¹⁹ World Health Organization (WHO). (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

employment, persons with disabilities reported discriminatory hiring practices. According to one participant, a 60-year old man with a physical disability, speaking in a focus group discussion:

Us who are disabled we are really in trouble, because if you go and ask for a job, they will instead give the job to one who is normal-bodied. Me, who is disabled, they will just say "Go and rest you can't do this job." ... Sometimes there are people who bring maize for work, to be given to people who clean the roads and rivers. But us who are disabled, if we go there it's very hard because they will just say "You, you are disabled you can't do this. Just go and rest."

Another participant, a 72-year old man with a physical disability speaking in a different focus group discussion, presented a parallel form of discrimination with respect to credit access: "Us who are disabled we find it difficult to get those loans. Loans which are there they just give those people who are normal-bodied."

With respect to the parallel issues of access to employment and credit, the research participants proposed multiple reasons behind the discrimination. These proposed reasons could be seen on a spectrum: at one end were the reasons that were based entirely upon misconceptions. At the other end of the spectrum were reasons for which the participants supported the logic behind the exclusion, even though they lamented being excluded.

Providing an example of a misconception about her capacities, a 26-year old woman with a physical disability spoke about her experiences with employment stigma after having successfully completed a hotel housekeeper training program. In the context of discussing how she had been called for interviews but not called back afterward, she stated:

Why don't [the hotels] employ me? They say there is a vacancy, I have what it takes to work there. But immediately, maybe when they see me that is, they feel like "No, maybe this person can't do this because of the way she is."

In the case of loans, some participants expressed the possibility that poor repayment rates of previous loan initiatives for persons with disabilities were partially responsible for their difficulties in securing loans. In a focus group in which loans were being discussed, a 30-year old man with a physical disability stated, "let them not punish us for the sins those other people did" in reference to previous loan programs for persons with disabilities that had low levels of repayment and were therefore deemed unsuccessful. In an attempt to differentiate his peer group from that of the previous programs and promote the potential of loans as a promising strategy to combat poverty, the participant continued, "Us, we can promise to return the money. It can be a good idea for [a lending agency] to re-start the program."

Another participant, a 70-year old man with a visual impairment further emphasized this dynamic in the same focus group discussion:

Those other people received money by saying "we can do this; we can do that." But they were just saying those things to access the money, even though they would not use it nicely. If I was to be given that money, I would fight hard to repay the loan.

According to a different participant, a 65-year old man with amputations caused by leprosy, persons with disabilities were denied loans because of a fear that they would be unable to protect the money. This man referenced a conversation with a local government official where the participant made a request for a loan, "Now what they [the government official] answered was 'If we give you the same money now and the thieves steal from you, what are you going to do?'" From the perspective of the research participant, the point about persons with disabilities protecting their loan was moot because of community solidarity, "How we answered that question was, we said 'We people we cannot just walk on our own; we walk with people who can help us."

Participants presented these previously-described barriers to acquiring money in terms of misconceptions or inappropriate generalizations. By contrast, there were also instances where participants presented barriers to acquiring money as understandable, although unfortunate. For example, when speaking of his poverty, a 64-year old man with physical and

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speech disabilities presented his inability to perform the tasks necessary for the jobs which were available; consequently, he was without income:

But living in poverty, we are really living in poverty. Like the others have said, when there is work, we people who are disabled we cannot do it. Even when you try to go there, they will disappoint you by saying "You, you cannot." And that is really the truth: you really cannot.

In addition to employment, the participants identified ways in which disability was a

barrier to acquiring money through entrepreneurship. Speaking in the context of wanting to

escape poverty to provide her young son with more opportunities, a 26-year old woman with a

physical disability that limited her capacity to walk reported barriers to engaging in lucrative

entrepreneurial activities:

Participant: It's very hard for you, a parent who is disabled, to take care of your child, to get them to school and to make sure that your child looks like other people's children whose parents are not disabled. It is hard because it is hard for me to find money.

Interviewer: Would your situation be any different if you did not have a disability but had the same amount of money, in terms of taking care of your children?

Participant: If I could, if I was just able-bodied I would...maybe going somewhere very far. I would walk long distances and do everything to please my child...for him to feel that he is also ok with life.

Interviewer: Can you tell me the things that you want to do for your child but you cannot do because you need to walk a long distance?

Participant: There are some people who come to me and say, "We want you to come work with us." The money they promise, it is a very huge amount of money. Then for me to go with my child that side, to care my child that side, it is very difficult. Again, to leave him behind, it is difficult.

Barriers to entrepreneurialism were not limited to the fulfillment of marketable tasks. One

participant, a 59-year old man whose physical disabilities meant that he relied on a wheelchair

for his mobility, performed shoe repair as a small business. Despite completing the work, he

was often unable to collect the money promised to him by clients. In explaining why people

choose to not pay him, the participant suspected that it was due to his lack of physical prowess,

speculating that, "People say 'because he cannot chase me, he cannot do anything. He cannot fight me."

Since the majority of the participants in this study were persons with disabilities themselves, the issues with respect to employment and entrepreneurship were typically related to the participants' own disabilities. Those participating in the study without disabilities were instead family members of persons with disabilities; in some cases, the barriers to acquiring money were related to caring for these family members. This situation was exemplified by the mother of a 9-year old girl with severe disabilities, who stated:

Like for me I will talk on behalf of my daughter. As you can see her, you have seen her, she cannot do anything; she just depends on me. It is me who can do everything for her... And I cannot do a business which will need me to walk or travel to go very far, leaving her. I cannot leave her.

Besides the barriers to acquiring money, participants also identified hardships in accessing goods (i.e., materials and supplies) that are generally available to persons without disabilities. For example, a 69-year old woman with a physical disability stated, "We do not get water from taps, it is down in the wells. Like for us who are disabled, going down there to fetch water in the wells, it is very hard for us." In addition to fetching water, this dynamic applied to firewood collection, gardening, and fishing. This dynamic, of not being able to do what others *just do*, meant that persons with disabilities a) were unable to access these resources, b) forewent opportunities to earn income from collecting and selling the resource, and/or c) incurred added costs to meet their basic needs. In the context of discussing income generation, one 55-year old man with a physical disability described a situation that also impacts his ability to head a household:

Cutting firewood in the bush, you can cut. But then you will fail to carry these things with you. But if you have something, say, after cutting your firewood, you give somebody money, that person can carry the firewood.

Difficulties in acquiring goods were typically related to physical tasks that were difficult to execute due to the participants' functioning. In a different vein, the participants with disabilities reported difficulties in receiving entitlements to which they were publicly eligible. In one of the communities, numerous participants reported problems with the distribution of relief food. At one point in time, persons with disabilities were offered 50kg of maize meal, but when they went to pick this up, they only received half of the amount. According to the participants, this discrepancy was entirely due to their status as persons with disabilities (it was unclear as to whether non-disabled individuals also received relief food). One participant explained the discrepancy in terms of political weakness and disempowerment:

Because the people who are disabled cannot say anything, since they are given... they are just being given. So, someone can make them to sign, even for things which are not there. They will tell you to sign, "We are going to give you, sign here." But they have [the supplies]...the total quantity of maize is 50kg, but they will give you less.

As previously mentioned, persons with disabilities faced challenges doing the things that others *just do.* Sometimes, these situations would entail additional expenses; otherwise the participants simply could not access a given resource. In most instances, these references were in relation to physical tasks. However for one family, this scenario applied to the education of their son with an intellectual disability. Although the son could independently walk to the neighbourhood school, the school would not accept him. According to the mother, "there are some schools where they can accept him, it is only that they are far and most of them are boarding schools whereby I cannot manage [the cost] to take him there." With respect to the schools that were far but not boarding school, these were geographically beyond walking distance and practically beyond the son's capacity to take affordable public transportation. As of the time of the interview, the combination of non-existent local services and available but cost-prohibitive services elsewhere, meant that this family went without. In this case, the disability of a family member did not cause poverty as-such, but the family's situation of poverty meant that

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they were not able to mitigate barriers that they faced for activities that their non-disabled neighbours *just do*.

Many of the dynamics by which disability was explicitly related to poverty were reported by both men and women. However, there was one situation that was experienced only by women: the abandonment of women with disabilities by their male partners after having children. The resultant dynamic was that the women had to care for young children as single mothers. As described by a 44-year old woman with a physical disability, "The father to that child does not care about the child because they are shy, or maybe people laugh at him, that he impregnated a disabled person." This issue emerged during a focus group discussion in which men and women participants contributed details about the ways in which parental responsibility was experienced differently between disabled men and women. Moreover, the participants spoke about family and societal pressures that discouraged fathers from taking responsibility for their children born of mothers with disabilities.

Not all references of poverty could be specifically linked with disability, at least not disability understood as a limitation of function. In Figure 2 we present an overview of these references. Following the format that we used in Figure 1, we have organized these in terms of difficulties in acquiring resources and increased expenses.

[Insert Figure 2 about here]

In presenting these results, we feel compelled to state that we have coded these accounts according to our analysis of the description of poverty provided by the participant and not their explicit statement of the relationship. Often, participants would explicitly state that their poverty was the result of their disability status, but then provide a description that we could neither directly nor specifically relate to functional limitations. For example, as part of a focus group discussion about the details of life with a disability in Western Province, a 60-year old

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man with a physical disability offered that "What I have seen in life is that if you are disabled but you are working, if you are doing a business, people will respect you for that." The follow up to that comment unfolded as follows:

Interviewer: You said that people, even if they have a disability, if they have a business they get respect while people who do not have businesses cannot get respect... 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.

Participant: 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 don't have – so you are not regarded... All that is brought because of being disabled.

In this exchange, it initially seemed possible to guide the participant into a comparison of the situation of persons with and without disabilities who experience similar (relatively privileged) economic status. Instead of making the comparison that the interviewer tried to facilitate, the participant opted – consciously or unconsciously – to make a comparison between people who experience wealth and those who experience poverty. If we understand disability to be a limitation of function, and not an economic status,²⁰ then there is neither a specific nor a direct link between the participant's account of poverty and disability, despite the participant's statement that there is a link. For the purposes of this analysis, therefore, we present this type

of account as being unrelated to disability.

Similar to the way in which we organized the accounts of poverty that were related to disability, we could organize these accounts into barriers in acquiring resources and increased expenses. Overwhelmingly, these are accounts of *poverty traps*: situations where pre-existing poverty leads to ongoing poverty.

²⁰ One of the findings of the primary research was that the status that the participants refer to as "disability" (Silozi = *buhole* or *buyanga*) could be understood in terms that are different from functional limitations; see Cleaver (2016), pp 88-90. Nonetheless, in policy and development circles, the dominant understanding of disability is one of functional limitations.

With respect to the acquisition of resources, participants reported difficulties accessing credit and earning income because of a lack of opportunities given their pre-existing poverty. One participant, the one who made the comment about the relation between business, wealth, and respect, also spoke about how people in poverty were unable to access informal sources of credit:

Asking for a credit from someone, they do not give us because they say, "Where are you going to get the money to pay us back?" So instead they will just say "No, we do not have [any money to loan you]."

In discussions about formal sources of credit, one participant with a physical disability who had more resources than most of the other participants with disabilities, mentioned the way in which pre-existing poverty made it likely that the others would default on their loans:

In the situation where we are now, poverty is too much. So, for someone who gets a loan, first he will think about improving his house. [They will think about] what they should eat, or maybe buy a blanket. Instead of starting to pay back the loan.

While recognizing the challenges of loans, this participant was simultaneously trying to secure loans for the local group of persons with disabilities. This task had been unsuccessful to that point; "[The loan agency] said they cannot give us a loan because we are not doing anything [to earn money]. They want people who are doing something for them to pay back." Although it could be true that the disability status of the members *contributed* to their lack of engagement in income-generation, this is neither direct, absolute, nor exclusive to persons with disabilities.

In relation to employment, many participants mentioned how their education was insufficient to secure job opportunities and therefore meant that they had no income. Most commonly, the reason behind the limited education was not the participants' disability status, but instead the inability to pay school and exam fees. Multiple participants spoke of their potential to escape poverty by "doing a business" (i.e., small-scale entrepreneurship). According to participants, the main barrier to the realization of their business plans was starter capital. Individual participants mentioned unique capital needs: hair dryers, a sewing machine, a business licence certificate, chickens, food provisions and small electronic items for resale, musical instruments, and wool thread, among others. In one case, a participant related his lack of fishing capital to increased expenses:

I get my fishnets and canal access from others on credit. But when I pay back the nets and the canals which I used, then at last I will just see that I have just worked for [the creditors]. If I was able to buy my own nets and my own canals, it was going to be better; I would have helped my grandchildren. I would not have any worries because I was going to provide for them.

Once more, although participants would sometimes rhetorically link their need for these items to their disabilities, it is difficult to see why the difficulties in acquiring this starter capital would be *exclusive* to persons with disabilities, rather than a shared experience of poverty that transcends the presence or absence of functional limitations.

In addition to the accounts of ongoing poverty that are rooted in a lack of opportunities

due to pre-existing poverty, some participants spoke of the ineffectiveness of distribution

programs as a mechanism to address the challenges of living with poverty. As reported by a 65-

year old man with multiple amputations subsequent to leprosy:

Even when you would sit without food or you die without food you cannot go there because if you go there you know that they will not give you food. Same thing if you go there to say, "I do not have blankets to cover myself." We have maybe 10 years without finding blankets to use in this ward.

Although this participant was speaking in the context of his situation as a person with a disability, the account was not specific to persons with disabilities. In this case, he referenced a specific government agency that he felt should be meeting the needs of people who were lacking things. In other accounts from this same participant, he referenced multiple sources of

support that could, should, or used to be in place, alternatively mentioning these as being for "people who are disabled" (Silozi = *lihole*) and "people who are suffering" (Silozi = *banyandi*).

Discussion:

In the primary research exploring the meaning of disability in Zambia's Western Province, participants spoke frequently and emphatically about poverty. Close examination of the data showed many instances in which poverty can be specifically and directly related to disability, when disability is understood to be a functional limitation. In multiple other accounts, poverty could not be linked specifically or directly to functional limitations, despite the participants' statements that poverty was due to disability.

The results that have been most interesting to us are those in which participants emphasized a link between poverty and disability while describing a situation of poverty that appeared to us to be unrelated to disability. We see at least two explanations for a mismatch between the participants' statements and our analysis. The first explanation is that there could be a relationship between disability and poverty, but that this is be non-specific and indirect. Given that our findings included ways in which disability led to poverty and ways in which preexisting poverty led to ongoing poverty, it stands to reason that these two findings can be combined such that disability leads to initial poverty which is then difficult to escape.

The second explanation is a function of the research context. One important aspect of the context was the significant economic gradient between the research participants and the field researcher (SC). Although the researcher approached the project with the intention of pursuing shared goals and authentic partnership with the participants, the structural inequality between the researcher and the participants likely influenced the way that the participants

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engaged in the study.²¹ Specifically, the participants made numerous explicit requests for material resources during the data collection period, despite the fact that the research team members repeatedly and emphatically declared that such things would not be provided during the recruitment and consent process. Since the research context was one where there was a significant wealth difference between the visiting researcher and the local participants – in this study about disability – it is reasonable to believe that participants might have emphasized their disability status when discussing a concern, they hoped the researcher would be willing to address: their situation of poverty.

We offer the first and second explanations to demonstrate that we have thought about these, but at this stage, it is not our priority to determine the plausibility of the first versus the second (let alone any alternative explanations). In fact, for us, an important finding from this secondary analysis was the extent to which there *was not* a mismatch between a) the participants' claims that their poverty was related to their disability and b) our analysis of their accounts. Stated differently, given the memorable uncomfortable and confusing experiences of fieldwork, we *expected that most* of the participants' accounts would have been cases of disability being linked to poverty in ways that we could not logically link. The fact that there were many accounts in which the link was specific and direct helps us change the way we understand the interactions of data collection.

Our finding that many of the accounts analyzed in this secondary analysis directly and specifically linked disability and poverty is congruent with a significant body of literature.²² In this sense, our findings support those of many other researchers in that the situation of persons with

²¹ Cleaver, S., Magalhães, L., Bond, V., Polatajko, H., & Nixon, S. (2016). Research principles and research experiences: critical reflection on conducting a PhD dissertation on global health and disability. *Disability and the Global South*, 3(2):1022-1043.

²² Eide A.H. & Ingstad B. (2011). *Disability and poverty: A global challenge*. Bristol, UK: Policy Press.; Grech (2016); Mitra et al. (2017); Pinilla-Roncancio, M. (2015). Disability and poverty: two related conditions. A review of the literature. *Revista de la Facultad de Medicina*, 63(Sup1):S113-23.; Yeo & Moore (2003).

disabilities truly is particular as compared to the general population. Poverty that occurs because of disability is an important case of structural inequity.

Beyond the instances where participants described their poverty in a way that we saw to be linked to their disability, it was often common for participants to describe their ongoing poverty as a function of pre-existing poverty. In this sense, the experience of persons with disabilities was likely common to that of the non-disabled poor of Western Zambia.

In societies with extensive poverty, it has been proposed that the poverty experienced by persons with disabilities is more likely to also be experienced by their neighbours without disabilities.²³ In these situations, it seems that persons with disabilities experience fewer socioeconomic disadvantages within their own societies. As societies develop economically, the opportunities to advance economically and escape poverty are not distributed equally; persons with disabilities are often left behind. This phenomenon of unequal development has been described as the *disability and development gap*.²⁴ This secondary analysis revealed ways in which poverty was particular to disability. Despite these particularities, the high overall prevalence of poverty in Western Province and commonalities of poverty experienced by persons with and without disabilities make it seem likely that Western Province has not yet experienced the disability and development gap.

The findings of this analysis have immediate relevance for poverty alleviation efforts both within and beyond our specific situation. These findings show that at least some poverty alleviation efforts should be specifically tailored to the situation of persons with disabilities in order to address their particular situations. The findings also demonstrate aspects where persons with disabilities share common aspects of poverty with others who are poor. There is therefore reason for large-scale poverty alleviation efforts to monitor the extent to which persons

²³ Groce, N. E., & Kett, M. (2013). *The Disability and Development Gap*. London: Leonard Cheshire Disability and Inclusive Development Centre.

²⁴ Groce & Kett (2013).

with disabilities are included. Conversely, these aspects of common cause are reasons for which persons with disabilities should consider allying themselves with the non-disabled poor. Finally, given the possibility of a disability development gap, all actors involved in development activities should consciously monitor and proactively improve the inclusion of persons with disabilities into their programming.

Some refer to the combined strategy of *disability-specific programming* and *disability-inclusive general programming* to be a "twin-track approach."²⁵ The results of this analysis support the pursuit of a twin-track approach with respect to disability for poverty alleviation and development efforts in Western Province, Zambia.

Conclusion:

This study helps to inform a twin-track approach to poverty alleviation action. The aspects of the poverty experience that are particular to persons with disabilities are potential targets for disability-specific action. Other aspects could be common to the experience of poverty for persons with and without disabilities and therefore opportunities for the inclusion of persons with disabilities into the mainstream social change movements.

²⁵ United Nations Development Program (UNDP). (2012). *Guidance Note: Applying the Conventions on the Rights of Persons with Disabilities in UNDP Programming*. See p. 17.

References

- Central Statistical Office (CSO). (2012). Zambia 2010 Census of population and housing, National analytical report. Lusaka: CSO. Retrieved July 14, 2017 from http://catalog.ihsn.org/index.php/catalog/4124
- Charlton, J.I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- Cleaver, S.R. (2016). Postcolonial Encounters with Disability: Exploring Disability and Ways Forward Together with Persons with Disabilities in Western Zambia (*Doctoral dissertation*). Available from Dissertations & Theses @ University of Toronto; ProQuest Dissertations & Theses Global (Order No. 10194206).
- Cleaver, S., Magalhães, L., Bond, V., Polatajko, H., & Nixon, S. (2016). Research principles and research experiences: critical reflection on conducting a PhD dissertation on global health and disability. *Disability and the Global South*, 3(2):1022-1043.
- Eide, A.H. & Loeb, M. (2006). *Living Conditions among People with Activity Limitations in Zambia. A National Representative Study.* Oslo: SINTEF Health Research.
- Eide A.H. & Ingstad B. (2011). *Disability and poverty: A global challenge*. Bristol, UK: Policy Press.
- Grech, S. (2016). Disability and poverty: Complex interactions and critical reframings. In: S. Grech & K. Soldatic (eds.), *Disability in the Global South,* (pp. 217-235). Cham, Switzerland: Springer International.
- Groce, N.E. (1999). General Issues in Research on Local Concepts and Beliefs about Disability.
 In: H. Holzer, A. Vreede, G. Weigt (eds.). *Disability in different cultures: Reflections on local concepts,* (pp. 285-296). Piscataway, NJ, USA: Transaction Publishers.
- Groce, N. E., & Kett, M. (2013). *The Disability and Development Gap*. London: Leonard Cheshire Disability and Inclusive Development Centre. Retrieved January 25, 2018 from: http:// www.ucl.ac.uk/leonard-cheshireresearch/research/publications/documents/working-papers/wp-21.pdf
- Masala, C. & Petretto, D.R. (2008). Disablement to enablement: Conceptual models of disability in the 20th century. *Disability and Rehabilitation*, 30(17), 1233-44
- Mitra, S., Palmer, M., Kim, H., Mont, D., & Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal*, 10(4):475-484.
- Pinilla-Roncancio, M. (2015). Disability and poverty: two related conditions. A review of the literature. *Revista de la Facultad de Medicina*, 63(Sup1):S113-23.
- United Nations Development Program (UNDP). (2012). *Guidance Note: Applying the Conventions on the Rights of Persons with Disabilities in UNDP Programming*. Retrieved July 21, 2017 from: http://www.undp.org/content/dam/undp/library/Poverty%20Reduction/Inclusive%20devel opment/DisabilityGuidance_Web41pgs.pdf
- World Health Organization (WHO). (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

- World Health Organization (WHO) & World Bank. (2011). *World report on disability*. Geneva: World Health Organization.
- Yeo, R. & Moore K. (2003) Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development*, 31(3), 571-90.
- Yeo, R. (2005). *Disability, poverty and the new development agenda.* Disability Knowledge and Research Programme. Retrieved July 21, 2017 from: http://r4d.dfid.gov.uk/PDF/Outputs/Disability/RedPov_agenda.pdf

Figures:

Figure 1: Direct and specific link between poverty and disability

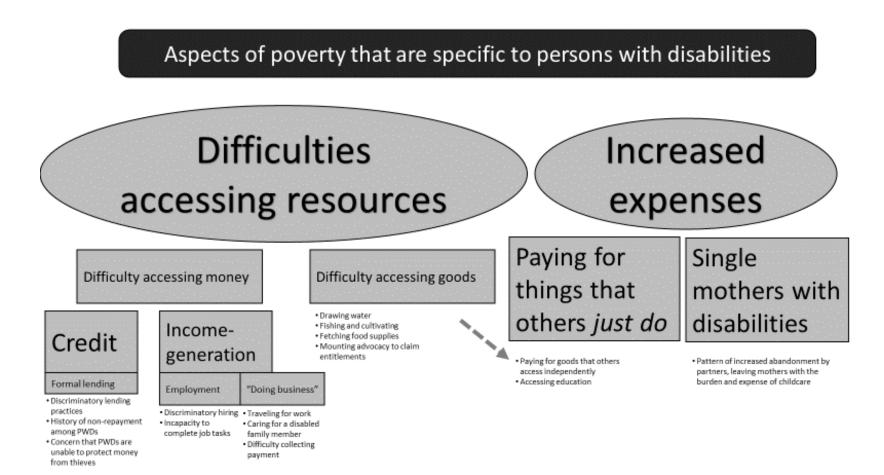


Figure 2: No direct link between poverty and disability

