PARENTING STRESS IN ZAMBIAN PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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Abstract

This dissertation examined the experiences of Zambian parents of children with developmental disabilities (DD) using the Perry (2004) stress model as a theoretical framework. The overall project was a sequential mixed methods design, including four distinct studies. **Study 1:** Semi-structured interviews with 15 Zambian mothers were used to explore what themes arose from discussions about factors contributing to the experience of raising a child with DD in Zambia. The twenty-five emergent themes included barriers to accessing services, challenges obtaining information, and the value of support provided by special education teachers and other parents of children with DD. **Study 2:** Questionnaires were administered to 76 Zambian caregivers of children with DD. Univariate analyses and hierarchical linear regressions were used to explore which factors were predictive of outcomes. Individuals with greater financial need (p = .001) and higher self-efficacy (p < .001) ratings were more likely to endorse positive outcomes related to having a child with DD. Participants who reported less financial need (p = .004), less frequent use of negative coping styles (p = .030), a greater number of sources of support available to them (p = .002), and greater self-efficacy (p = .010) also endorsed higher quality of life ratings. Finally, greater financial need (p = .010) and more frequent use of negative coping (p = .001) were predictive of poorer mental health. **Study 3:** The third study examined the relationship between executive functions and coping in a subsample of 44 participants from Study 2, using additional questionnaire measures. After controlling for parents' education level and financial need, executive function alone accounted for 56% of the variance in active coping, 30% of the variance in support coping, and 25% of the variance in negative coping. **Study 4:** Finally, in order to solicit participant input on our interpretations of the results, a focus group was conducted with a subsample of 10 caregivers from Study 2. Select results from Studies 1 and 2 were presented to the group and participants were able to provide further context to enhance our understanding of the factors contributing to parenting stress among Zambian parents of children with DD. Overall this dissertation presents an in-depth examination of the experiences of Zambian mothers of children with DD, and directions for future research that may further benefit this population.

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Study 1: A Qualitative Exploration of the Experiences of Zambian Parents who have Children with Developmental Disabilities

General Introduction

Parents of children with developmental disabilities (DD) in low-income countries such as Zambia are underrepresented in research despite the impact that having a child with DD can have on a family. Research by Tomlinson et al. (2014) suggests that the prevalence of DD is estimated at 10.4/1000 worldwide with higher rates among lower income countries. For example, in estimates provided by the World Health Organization (2011) disability prevalence rates in adults ranged from 11.8% in higher income countries to 18.0% in lower income countries. Due to local government and not-for-profit/non-governmental organization efforts, high infant mortality rates in the developing world have been declining; however, the factors that have historically contributed to high infant mortality rates (e.g., poverty, malnutrition) are also related to the prevalence of DD in children who survive the first five years of life (Black et al., 2003; Grantham-McGreggor et al., 2007; Lawn et al., 2005). Therefore, as a result of declining infant mortality rates, and without a significant change in economic, health, and living conditions, rates of DD in low-income countries may be increasing. In fact, Mckenzie and colleagues (2013) estimate that DD is the largest impairment grouping on the continent of Africa. Despite these data, little is known of the impact of caring for a child with DD on parents residing in low-income nations such as Zambia.

Research from various countries suggests that parents of children with DD, including intellectual disability, autism spectrum disorder, cerebral palsy, Down syndrome, and genetic disorders, experience greater levels of stress than parents of typically developing children (e.g., Cantwell et al., 2014; Gallagher et al., 2010; Gupta, 2007). Parenting stress is described by Abidin (1995) as the mismatch between the perceived demands of parenting and available resources to meet those demands. This increased stress has been shown to have negative impacts on the parents, including poor sleep quality (Gallagher et al., 2014), poor physical health (Cantwell et al., 2014), increased risk of depression (Bishop et al., 2007), and poor memory for everyday tasks (Lovell et al., 2014), among others.

No studies were found comparing levels of parent stress between parents of children with DD and parents of typically developing children in Zambia; however, research exploring experiences of Zambian parents suggests that parents of children with DD experience unique frustrations that are likely to increase their stress. These challenges include a need for more institutional-level support, increased rates of poverty, marital strain, and social stigma, among others (Chiluba & Moyo, 2017; Nyoni & Serpell, 2012; Mung'omba, 2008; Trani & Loeb, 2012).

Outcomes of parents of children with DD are not uniform, however, and many parents also report positive outcomes, including personal growth and other positive gains, related to having a child with DD (Blacher & Baker, 2007; Minnes et al., 2015). Additionally, the resources available for meeting these increased demands vary greatly depending on the parent's individual resources and on the supports available through community- and institutional-level systems (Nyoni & Serpell, 2012). Promoting positive outcomes in parents is important as they are the primary caregivers and parents experiencing a great deal of parent stress will be less effective at caring for their children. Chiluba and Moyo (2017) report a trend towards community-based rehabilitation of children with disabilities in Zambia. A greater emphasis is now placed on the involvement and responsibility of parents in the provision of rehabilitation and healthcare interventions for their children. It is therefore important that we consider parent health and well-being as parent stress not only affects them but has the potential to affect their capacity to support their children as well. To fully understand the stress experiences of Zambian parents of children with developmental disabilities it is important to examine the way outcomes of parents are affected by the multitude of variables at play.

The overall objective of this study was to explore the experiences of urban-dwelling Zambian parents who have a child with a developmental disability. Developing a clearer understanding of the experiences of Zambian parents of children with DD may help provide direction for intervention and allow government agencies, non-profit agencies, clinicians, educators, and service providers understand how to better support these parents. The long-term goals of this project include the provision of information that can be used to inform current programs in Zambia, and the development of future programs. For example, understanding which factors are associated with negative outcomes can help service providers and government agencies identify parents who are at risk for increased parenting stress and the negative outcomes associated with parenting stress. These service providers and agencies can then allocate time and resources more efficiently to those with the greatest need. Understanding which resources and supports are more likely to be associated with positive outcomes can help provide direction for more targeted intervention.

A sequential mixed methods design - in which quantitative and qualitative data are collected at different time points - was used to explore this topic. Creswell and Plano Clark (2007) argue that mixed methods procedures balance the weaknesses inherent in one method (i.e., quantitative vs. qualitative) with the strengths of the other. In mixed methods research designs, quantitative and qualitative data can be generated and compared to determine their convergence, differences or combination thereof. Mixed methods research designs also provide researchers with the flexibility to use cultural knowledge and anecdotal or clinical observations as evidence and allow for the use of qualitative results to aid the interpretation of quantitative results, resulting in richer – and hopefully more accurate – interpretations (Creswell & Plano Clark, 2006). In using a mixed methods design, my goal was to gain a more comprehensive and nuanced view of this under-researched subject area than I would have obtained with a single methodological approach.

In Study 1, a semi-structured interview was used to broadly explore factors contributing to the experience of raising a child with DD in Zambia. In Study 2, data obtained from a researcher-administered questionnaire was used to explore which factors are predictive of positive and/or negative outcomes in Zambian parents of children with DD. In Study 3, additional questionnaire data was used to more closely examine the relationship between executive functions and coping. Finally, in Study 4, a focus group was used to solicit participant input on the results of Studies 1 and 2. This final study was important to include, as research conducted by Western researchers continues to be informed by European Western values, ethics, and norms (Marshall & Batten, 2003). In conducting my dissertation research, I was cognizant of the ways that, by being a researcher from a Western institution conducting research on a marginalized group, I could be replicating power dynamics that already exist between high-income and low-income nations. I have experience as a woman of Zambian descent; however, I do not have experience as a parent, let alone as a parent raising a child with DD. I have also largely been educated outside of Zambia (from high school/secondary school onwards) unlike most of the parents who participated in these studies. Finally, I am conscious of the fact that I occupy a position of economic privilege in comparison to many of the parents who participated in this dissertation. Throughout this project I attempted to maintain awareness of how my own unique background may have been impacting my judgements, as well as the experiences of the participants with whom I was interacting. It was important to me that I present as accurate and holistic a picture of the experiences of the parents who participated in this dissertation as possible and make efforts to incorporate their voices and perspectives as much as possible. Providing research participants with the opportunity to provide feedback on our interpretations of the results was judged to be a small but meaningful step towards ‘decolonizing’ the research methodology.

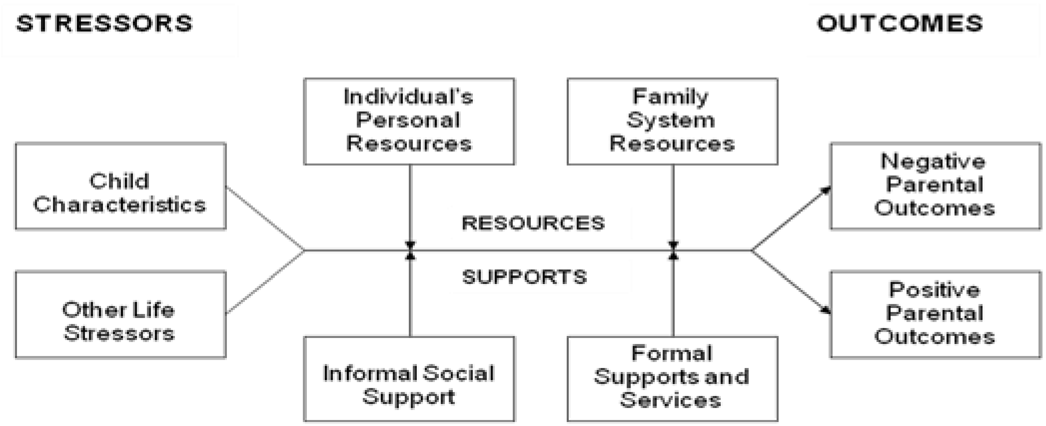
Study 1: A Qualitative Exploration of the Experiences of Zambian Mothers who have Children with Developmental Disabilities

Women and girls overwhelmingly shoulder the responsibility for family caregiving and experience greater stress, reduced opportunity for employment, and often end up caring for others even in their own advanced age (Mckenzie et al., 2013). Outcomes of parents of children with DD are also gendered, with research from various countries suggesting that women face unique barriers to well-being (e.g., Brekke & Nadim, 2017; van der Mark et al., 2019). Additionally, a review of literature relevant to DD in Africa indicates that mothers, sisters, and grandmothers act as single parents of children with DD because fathers may be unable or unwilling to stay with the disabled child and the mother (Mckenzie et al., 2013). However, to date, there has not been a broad exploration of the various factors that may impact the experiences of mothers of children with DD in Zambia.

The Perry Stress Model (2004) presents a comprehensive model for understanding stress in families of children with DD. The model contains four major components (stressors, resources, supports, and outcomes) which are each divided into two subdomains (See Figure 1). Stressors in this model include the major and minor stressful stimuli that may occur in the lives of parents of children with DD, including child characteristics (e.g., adaptive skills) and other life stressors (e.g., loss of a loved one). The Perry Stress Model (2004) also emphasizes the importance of examining resources (personal and family) and supports (from informal social networks and formal support services) and their impact on both the positive and negative outcomes associated with caring for a child with DD. The Perry (2004) Stress Model therefore provides a useful framework for considering the ways in which Zambian parents may have unique experiences across each of the four major components as a result of social, historical, cultural, economic, or institutional factors.

Figure 1

The Perry (2004) Stress Model



Mothers of children with DD in Zambia may be more likely to face certain stressors and, while the child characteristics associated with certain disorders may be universal, the meaning ascribed to these characteristics, and the stress they subsequently engender may vary depending on sociocultural context. For example, social stigma is a concern for many Zambian parents (Loeb et al., 2008). In Zambia, the presence of disability may be seen as the consequence of social–cultural and religious misfortunes directed to the family and may result in the individual with impairment being seen as “unclean” (Mung’omba, 2008). In a study by Nyoni and Serpell (2012), Zambian parents of children with autism reported experiencing blame or moral criticism for their child’s behaviour and having family members suspect witchcraft or a breach of cultural traditions as being the cause of the child’s condition. Overall, there are a number of possible stressors that may be impacted by culture and environment and may subsequently uniquely affect Zambian parents.

Culturally-related differences in beliefs about disability and coping styles, as well as culturally- or economically-related variability in family system resources may also affect the experiences of mothers of children with DD in Zambia. Nyoni and Serpell (2012) found that all of the parents they interviewed reported experiencing some impact of the child's difficulty on their marriage, but one father reported that, despite the added difficulties, his child's condition had brought him and his wife closer together. For the couples that experienced marital difficulty, there was some indication that this was sometimes related to cultural stigma-related factors such as a parent's failure to accept the child's condition, one parent suspecting the other parent's family background of being the cause of the child's condition, or conflicts resulting from the financial strain of providing care for the chid with DD (Nyoni & Serpell, 2012).

The social support experiences of mothers of children with DD in Zambia are also likely tied to cultural beliefs about community support and disability, and institutional supports are likely constrained by the economic limitations of living in a developing nation. For example, Mung'omba (2008) suggests that, without direct intervention to address the high levels of poverty in Zambia, the effectiveness of institutional-level supports for individuals with intellectual disabilities is limited. Similarly, in the study by Nyoni and Serpell (2012), parents expressed frustration regarding the limited educational options for their children in Zambia and the insensitivity and social stigma that they perceived from the general public and professionals at health facilities. Additionally, high levels of social stigma in Zambia can prevent parents from reaching out for support or accessing services (Donald et al., 2015) and social stigma or shame may prevent extended family members from helping to care for the child.

Much of the research on the experiences of parents of children with DD suggests that experiences of parents are not uniform and many parents experience both positive and negative outcomes (Bayat, 2007; Greeff & Nolting, 2013; Minnes et al., 2015). However, due to a lack of research, it is unclear how Zambian mothers understand their overall experiences.

Study Objectives

Existing research has established the negative impact that parenting stress can have on the outcomes of parents and children (Bishop et al., 2007; Cantwell et al., 2014; Gallagher et al., 2014); however, few studies have examined the experiences of parents of children with DD in Zambia, and no studies were found specifically examining parenting stress in female caregivers of children with DD in Zambia. Existing studies examining the experiences of Zambian parents of children with DD tend to focus on the difficulties parents report; however, research conducted outside of Zambia suggests that parents of children with DD may experience positive as well as negative outcomes as a result of having a child with DD. Additionally, research suggests that outcomes of parents are gendered, such that women face unique challenges as a result of parenting a child with DD (e.g., Brekke & Nadim, 2017; van der Mark et al., 2019). The goal of the present study was to explore the experiences of urban-dwelling Zambian mothers who have a child with DD, with a particular focus on exploring positive as well as negative outcomes. The study used the Perry (2004) stress model as a theoretical framework to engage in a multifaceted exploration of the experiences of these women. Specifically, the main objectives were to explore the stressors, resources, supports, and outcomes reported by these parents.

Methods

A semi-structured interview was conducted with 15 Zambian parents of children with DD. The interview guide (Appendix A) was developed by Luthra (2018) based on Khanlou et al. (2017), Desai et al. (2012), and Daudji et al. (2011). Items on the interview guide enquire about the eight components of the Perry (2004) Stress Model, as well as the possible influence of culture on these components.

Participants

Thirteen participants were mothers of children with DD, and two participants were grandmothers who were primary caregivers of their grandchildren with DD. Half of the respondents had a secondary school level of education, one respondent had less than a seventh-grade level of education, and five respondents had completed a college or university program. Seven respondents reported being employed outside the home in diverse occupations that included housekeeper, library assistant, and real estate agent, among others. Additional demographic information is displayed in Table 1.

Table 1

Characteristics of Study Participants

Demographics of Participants	Participants (*N* = 15)
Caregiver's age in years	
Mean	41.7 years
Range	26 – 57 years
Caregiver's marital status	
Currently married	8 (53%)
Single (never married, divorced, widowed)	7 (47%)
Child's age in years	
Mean	11.67 years
Range	5 – 20 years
Child's sex	
Male	9 (60%)
Female	6 (40%)

All participants were required to be fluent in English to promote a more standardized administration of the measures. This allowed the interviewer to pose all questions to participants in English. However, although the interviews where primarily conducted in English, participants often used terms from major local languages (i.e., iciBemba, iciNyanja), even when speaking primarily in English. Most people living in Zambia are multilingual and mixing local language with English is commonplace in everyday discourse. Allowing participants to do so during the interview was thought to promote greater comfort and freedom of expression amongst participants. All participants were also urban-dwelling parents, residing in the capital city of Zambia: Lusaka.

Lusaka Demographics

Lusaka is the most populous city in Zambia, with an estimated urban population of 2.5 million at the time of the 2010 census (Zambia Statistics Agency, 2014). English is the official language of communication in Lusaka Province (in which Lusaka city is located); however, when Lusaka residents were asked what language they most commonly use to communicate in their day to day life in the 2010 Census, iciNyanja was endorsed by 61.9% of respondents. English was the third most common response, endorsed by only 6.2% of respondents in Lusaka Province overall, and 6.9% of urban-dwelling residents specifically (Zambia Statistics Agency, 2014).

When comparing wealth distribution across provinces, Lusaka Province has the highest percentage of the population (51%) in the highest wealth quintile in the country and the lowest percentage of the population in the lowest wealth quintile (1.8%; Zambia Statistics Agency, 2018). In Lusaka Province, 54% of children are estimated to be residing with both parents, while 20.5% have a living father but reside with only their mother (Zambia Statistics Agency, 2020).

Overall, 80.0% of women and 89.6% of men in Zambia aged 15-49 are estimated to be literate in either English or one of the seven official vernacular languages (Zambia Statistics Agency, 2014). Statistics on English *fluency* in Zambia are unclear; however, English is the main language of instruction in Zambian schools so statistics of educational attainment and literacy may be used to provide a rough estimate. When female educational attainment was examined in Zambia's country-wide 2018 Demographic Health Survey, 10.6% of women and girls (school-aged or older) residing in Lusaka Province had no education, 32.6% had some primary school education (10.4% completed primary), 27.8% had some secondary school education (10.8 completed secondary), and 7.4% had pursued higher education (Zambia Statistics Agency, 2020). Overall, the median years of school completed was 6.5

years. Educational attainment rates of males in Lusaka Province were similar to those of females (Zambia Statistics Agency, 2018).

When compared to the demographics of Lusaka Province detailed above, this study's sample appears to be biased towards having greater academic achievement, possibly due to our requirement that participants be fluent in English. As a result, they may not be representative of all caregivers of children with DD in the region, let alone the country.

Procedures

As with all studies in this dissertation, this study received approval from York University's ethics review board prior to commencement. I conducted the interviews in August 2017 and December 2018. Of the 15 interviews, one was conducted over the telephone, four were conducted in the home of the participant, one was conducted at the home of the participant's friend, and the remaining 10 interviews were conducted in a private room at one of the special needs schools. All participants provided informed written consent to participate in the study (Appendix B) and to be audio recorded (Appendix C) prior to each interview. The mother who completed the interview over the phone had an in-person meeting to obtain informed consent prior to scheduling the phone interview. With this participant, informed consent was then re-established verbally at the beginning of the phone interview. Interviews were approximately 30 minutes in length, on average, and ranged from 20 to 45 minutes.

Participants were recruited through purposive sampling. Specifically, I contacted schools, hospitals, and non-governmental organizations that provided specialized services for children with special needs. The organizations that agreed to circulate information about the study were then provided with flyers to circulate to the parents. Additionally, some organizations had representatives (e.g., teachers) act as intermediaries to connect interested parents with me. Parents who participated in the study were then asked to share information about the study with any other parents they knew who might be interested in participating as well. All participants received an honorarium of approximately $30 (provided in local currency; see Appendix D for the receipt for the honorarium) for participating in the study. Eligibility for participation in the study included (a) being a primary caregiver of at least one child between the ages of 0-21 with any type of DD (as identified by the parent), and (b) the respondent having sufficient English language proficiency to participate in the interview.

Data Analysis

All interviews were audio recorded and then transcribed verbatim. Portions of the text that were in local languages were then translated to English by me but were marked with a different font colour in order to distinguish them from text that was originally spoken in English and did not require translation. The text was then analyzed in *NVivo 12 Pro*: a qualitative data analysis computer software package that promotes ease of text organization and synthesis. An inductive approach was used to analyze the data. All transcripts were reviewed several times and impressions and other comments were then made throughout the document. After notes were taken, the transcripts were then re-read, the emergent framework was used to group the data, and thematic analysis was applied to synthesize the notes into more specific themes.

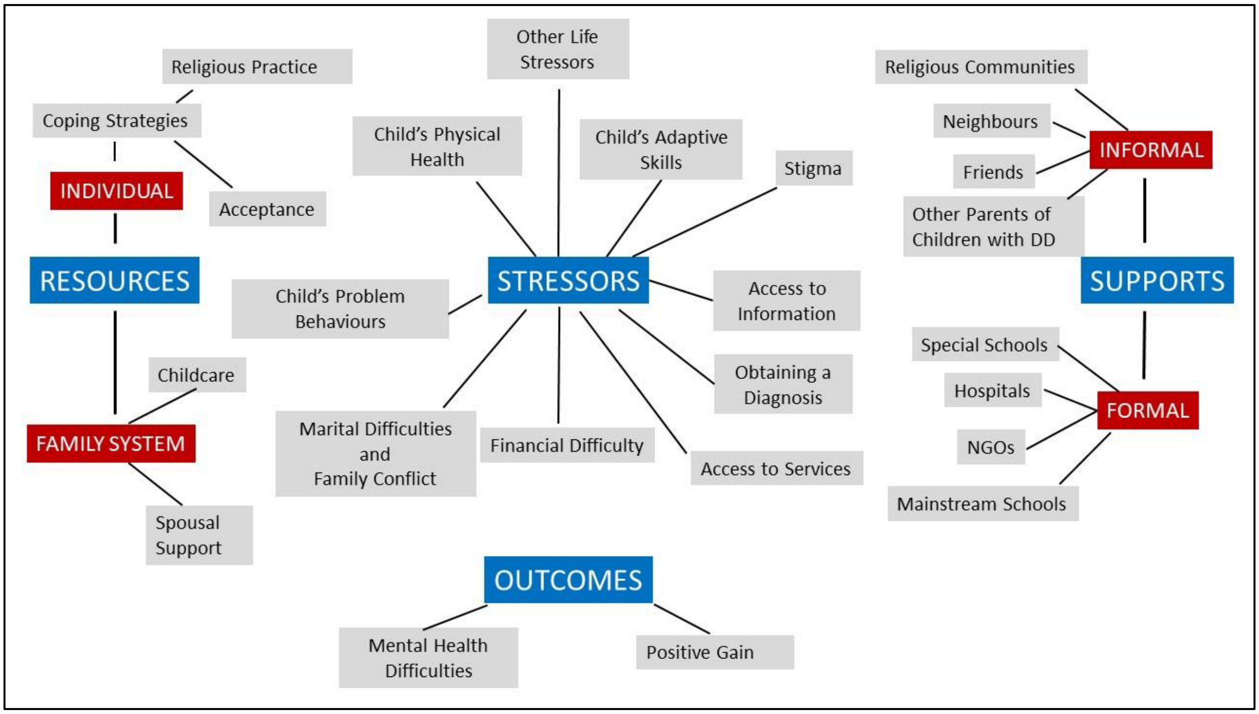
Three interviews were coded independently by me and two of my committee members. We met to compare our results for consistency and carefully discuss the themes we applied to those three transcripts. Our interpretations were similar and I proceeded to code the remainder of the transcripts using the same approach I had used for the first three. When coding was complete, repetitions in the data within each transcript and across different transcripts were used to establish themes, as recommended by Ryan and Bernard (2003). The transcripts were then re-read to identify direct quotations that were particularly representative of each theme. Similar themes were then clustered together, and clusters were given a descriptive label that communicated the nature of the theme. Once themes were established, I made inferences about the themes and summarized the data. I then presented these themes, along with quotes that exemplified the themes, to members of my research laboratory. Feedback from this presentation was carefully considered and informed my final interpretation of the data.

Results

The themes that emerged from the interviews largely fit into the broad categories defined by the Perry Stress Model. Some themes emerged from parents having consistent responses to questions in the semi-structured interview guide (Appendix A). However, a number of new themes emerged that were not explicitly tied to specific questions in the interview guide. All themes were organized using the Perry Stress Model as a guiding framework (Figure 2).

Figure 2

Thematic Map Illustrating the Emergent Themes



Stressors

Mothers in this study endorsed a number of stressors that impacted their experience of raising a child with a developmental disability in Lusaka. Some of the stressors were related to the child's condition, some were unique to the parent's individual situation, and still others were environmental and shared by a number of caregivers in the study who lived in similar conditions.

Child Characteristics

Six mothers described the ways in which their child's adaptive skill level (i.e., self-help skills such as not being able to feed or bathe oneself) played a significant role in their experience of raising the child. Similarly, seven mothers described the negative impact of their child's problem behaviours (e.g., destroying property, physical aggression). Challenges related to low adaptive skills included the child being less capable of helping out around the home or the child being less able to communicate their wants and needs with their parent. For mothers who had children with greater adaptive skills and fewer problem behaviours this was noted as something that had a positive impact on their lives. Parents whose children were completely dependent on them also reported that this limited their opportunities for social interaction or the pursuit of employment outside the home. While some mothers were able to manage this by negotiating childcare with other family members or friends this was made more difficult for caregivers of children with problem behaviours.

Mothers who reported that their children exhibited problem behaviours reported that their children needed to be watched with more vigilance and it was, therefore, more difficult to find someone who would be able to watch the child in the absence of the parent. For example, one mother of four children complained:

> She will do things that would really frustrate everyone like being very active doing things like running up and down, getting things like this, that you would not want her to be playing with.

> For example, she will get anything, or eat anything, or even drink it - anything that would even be dangerous for her … so it was a big challenge because I would just be monitoring what she is doing, where she is, and it was like every time we are sitting … we think every 2 minutes, “where is [child]? What is she doing?”

A few parents also reported that the child’s problem behaviours increased the difficulty in finding a school that would work with the child. Similarly, a few mothers reported that their child’s problem behaviours negatively impacted their relationships with family, friends, and neighbours. For example, one mother described some of her neighbours as being more compassionate of her situation while other neighbours were less tolerant of her child’s behaviour:

> The other neighbors they did not like because he was beating their children, but even them, there were children who were being beaten. But they were also aware of the prayers made for him so they would understand him. But, with [other neighbours] they would complain about what he did.

When mothers were able to find schools, family, friends, or neighbours who had patience for the child and were willing to work with the child, this was described as a significant source of support. For problem behaviours that potentially impacted the safety of the child (e.g., impulsive behaviours such as running away from the home or ingesting unsafe items), mothers reported increased stress related to the safety of their child. These mothers described the many ways in which such behaviours impacted the whole family and resulted in family decisions, such as where to live, being constrained by the child’s problem behaviour.

Nine mothers positively commented on the progress that their child had made over time; describing the ways that their child had improved, and indicating that they were grateful for these improvements. As mothers took note of the progress that their children made over time this made them more hopeful that, despite the remaining additional challenges, their child would continue to improve over time. Further, noting such progress in their children helped give mothers confidence in their ability to help their child. Parents also reported that remembering how much their child had improved gave them extra patience, strength, and fortitude in moments when their experience was particularly challenging. One mother noted that, when she becomes frustrated with her child's problem behaviours and is tempted to spank him, she is reminded to, instead, continue to pray for him because of the progress he has made so far.

Parents attributed their child's progress over time to many things; including growth and maturity, prayer and divine intervention, the parent's own efforts, and professional interventions or special education programs. Some such intervention and special programs encouraged the participation of caregivers so that they would be able to carry on the work with their children at home. Parents reported feeling empowered by attending such programs and many caregivers reported feeling as though the child's success depended on the parent's efforts to learn how to best support their child.

In addition to the progress they saw in their own children, mothers also reported feeling encouraged by comparisons they made between their child and other children with special needs. Some reported that seeing other children with similar conditions to their own child who were "doing well" gave them hope that their child may also improve. Additionally, mothers who saw children whom they perceived to be struggling more than their own child felt grateful and encouraged by their own child's skills. For example, one mother of three reported:

> It is not hopeless. If anything, he is much, much better than many other children that have this. He is very normal and able to talk; he is able to articulate, he is able to do so much so they always encouraged me and said it wasn't a hopeless situation and I think that is what gave me the courage to forge ahead and do what I've done for him.

Four mothers reported that the main source of stress related to their child's condition was their child's physical health. For children that had challenges with breathing or eating caregivers reported a great deal of stress related to maintaining their child's health. Additionally, these mothers reported that physical disabilities or serious health concerns induced financial stress as they necessitated surgery, other costly medical interventions, or specialized equipment.

Obtaining a Diagnosis

The path to obtaining a diagnosis differed, with some mothers having the child's issues identified immediately in the hospital when the child was delivered, and other parents having issues identified later when they took their child to the clinic for routine developmental check-ups for children under the age of 5. For some children, challenges were first noted by the parents themselves or by family members as the child failed to meet developmental milestones. Finally, for other children, concerns were only identified once they entered the school system and mainstream education programs reported that they would not be able to meet the needs of the child. For one parent, the delay in obtaining a diagnosis for her daughter was a source of sadness as this delayed her child's access to special education supports and she felt this had limited her child's opportunity to progress. This mother described her frustration in this way:

> I feel that when she was young that was the time that we were supposed to know but we didn't - up [until she was] 13 years, when we found out she should go to special school. So that is my regret, to say at least when she was young if we were able to know they would help her more and more.

One consequence of failing to obtain an accurate diagnosis for a child was that it sometimes limited the parent's ability to enroll their child in special education services and interventions.

For caregivers who were able to obtain an accurate diagnosis, it significantly reduced their stress and increased their confidence regarding their ability to raise their child. Five mothers of children of various ages and with a variety of needs had not obtained a clear and specific diagnosis at the time of the interview. Parents reported that their child’s condition was described to them by clinicians as “brain damage” or “slowness in learning or growing”. Some descriptions of the information provided by clinicians were unscientific and vague. For example, one parent reported that a clinician told her that a fall her child had sustained “caused her brain to shrink” and that this was the origin of the child’s challenges. Among the children in the sample that had a diagnosis, the majority were diagnosed with cerebral palsy: a loosely defined disorder of variable etiology describing challenges in movement and muscle growth that may or may not be accompanied by cognitive challenges (Kavcic & Vodusek, 2005). Some mothers reported receiving the child’s diagnosis when international doctors were brought into the country by an internationally funded NGO to diagnose a number of children who were receiving services from that organization.

Access to Information

All ten mothers who had received a diagnosis for their child reported that, once the diagnosis was received, they struggled to understand what that diagnosis meant and how they needed to parent their child as a result of the child’s needs. Other mothers were a significant source of information and support to one another in this regard. As parents interacted with other parents whose children had special needs, they came to understand their child’s needs better by comparing them to other children who displayed characteristics that they perceived as similar to those of their own child. Interacting with other parents was described as a significant source of support for many mothers, as it provided avenues for parents to seek advice and obtain information that may be relevant for their children as well.

Literacy and access to information on the internet was also noted as a significant source of relief in this regard. Mothers who were able to obtain information online recognized their privilege in this regard and described it as a necessary resource for their child's continued improvement. For these mothers, knowledge obtained through the internet filled a gap left by the perceived paucity of available services. For example, one mother who works as a teacher reported that:

> Maybe this fact that these facilities are not there, and because they're not there, the condition that he has is not widely spoken about and people don't really understand it. I and my family have privilege because we have extensively read about [child's name]'s condition, even on the internet. Despite having no facilities, we still take an interest to know what really it is and what's best for him, so at least we know.

Five parents reported having healthcare professionals who were knowledgeable about their child's disability-related needs and took time to counsel and explain things to caregivers; however, three of those five parents also described negative experiences that they had with other healthcare professionals. Additionally, the majority of parents reported either struggling to obtain supplementary information from clinics and healthcare professionals, or not understanding the information provided. One single mother recounted her attempts to obtain information from the clinics this way:

> Most of the people – when I try to find out they just tell me "go, you can just check most of the information [on] the [internet]. They just tell me the surface of the information, not the deeper. "No, try to find out from the net." And I'm not on a phone that can go on the net, so I don't … They will just say, "no, actually we're really busy. There are a lot of people so you can't expect a lot".

Access to Services and Interventions

Overall, reported barriers to accessing services and interventions included lack of available services in the community (or country as a whole), financial limitations, and lack of transportation. Once the child's needs were identified, eight mothers reported that they struggled to find services to support their child. A few of these mothers were made aware of interventions (e.g., surgery to improve the child's mobility) that were not available or had a significant cost associated with them. Additionally, sometimes mothers identified products, services, or interventions that may be useful for their child but did not know whether or not the services were available in Lusaka. It was notable that these caregivers possessed good information-finding skills as they were resourceful enough to find out about these products, services, or interventions, but still struggled to find out whether or not these services were available and how to obtain them. For example, one mother lamented:

> Because I'm on Facebook groups that have ADHD, sensory processing disorders, all these other things, I see people post about things that I think might be of help to him, but I don't know if they are available here. Things like weighted blankets because of his sensory issues.

Transportation concerns were mainly related to financial limitations and lack of accessibility due to the child's physical condition. For example, one parent who was able to transport her child to school reported the difficulty that other caregivers faced in transporting their own children to a special school:

> Some have failed to bring [the child] to school because, even with a wheelchair – because the bus you can't afford, taxi you can't afford. So if there was a bus or ferry that took children to school, most of the caregivers would be happy to bring their children to school.

Sometimes parents found out that a resource that would have been helpful to them had existed for some time, but they had not been made aware of it. One mother who struggled to transport her physically disabled child reported:

> I had to put him on my back and my son is tall. So I used to get tired but I prayed about it and one of my friends from physio told me “go to the orthopedic section. They have wheelchairs. I think it will help you”. So I went there and explained to the doctor. “Bring your son and we will see him.” I took him there. So they said “okay, no problem”. They gave me [a wheelchair] for free. So from there it went very easy for me.

This anecdote highlights the manner in which, for many parents, awareness of social services and beneficial resources was often obtained through word of mouth from other parents who had children with similar needs. Overall, the information that parents provided to one another was a necessary complement to the information being sought through clinics and special education programs.

Financial Difficulties

Twelve mothers described having financial difficulties and many of these mothers reported that financial needs were their greatest source of stress. For some parents financial difficulties were a source of stress primarily because they limited the parent’s ability to provide for needs related to the child’s condition, whereas other caregivers reported stress because of the threat to survival brought on by poverty more generally. As previously alluded to, financial difficulties presented a barrier for some families to accessing interventions and supports necessitated by the child’s needs. Additionally, financial difficulties resulted in stress for many caregivers as worrying about food, housing, and other needs simply presented another challenge for caregivers to worry about. As one single mother put it, “[my child] needs soap, she needs diapers; everything here we buy, including water. There’s no free things”.

Additionally, many mothers reported that the child’s needs contributed to financial challenges as caring for the child limited the caregiver’s ability to seek employment. For caregivers who were single, these challenges were made more significant by the absence of a partner with whom to share the burden of financial expenses and caregiving duties. Some single caregivers alluded to challenges related to obtaining financial support from absent fathers, while others were able to fill the gap with support from other family members. Three caregivers in this sample sought support from absent ex-partners by pursuing legal action; however, this was not always successful. The mothers reported that, despite the courts ordering these ex-partners to provide a certain amount of child support, the partners were still able to avoid making payments. For single caregivers who received no support from their ex-partners or their families, the situation was particularly dire.

Five mothers described experiencing challenges related to pursuing employment. For example, a few mothers reported that it was a challenge to know whether they would best serve their child by devoting their time to employment in order to provide financially or by supporting the child with their personal time. One mother reported that her child's intervention program required parent involvement and required a significant amount of transportation such that she could not have her child participate in these services while also working. This mother had to make the difficult decision to not take her child to intervention so that she could work and provide for the child's basic needs. Another mother reported experiencing guilt as she found it necessary to work but felt that this did not allow her to spend enough time helping and supporting her child once she got home. This mother shared:

> It has affected me sometimes and … sometimes I would feel that when I was working that maybe I'm not spending enough time on him because he always needed a little help and support, especially when he is doing his homework and - you know? So sometimes I felt like I wasn't giving him much time.

Marital Difficulties and Family Conflict

Unfortunately, five mothers alluded to marital and family conflict as a significant stressor in their lives. Sometimes these difficulties were related to the child's condition, while other times the marital difficulties simply made it more difficult for the primary caregiver to care for the child due to the strain of the marital or family relationship. Some mothers reported that their spouse's failure to accept or understand the child's condition could result in the father blaming the mother or feeling justified in abandoning the family. For example, a single mother described her experience in this way:

> He would say "I think you're not the woman for me because you have a disabled child when others have children that are able to do all sorts of things" … I called him [and he told me] that this is the woman I'm going to marry ... I called my in-law and explained, and she said, "that's how men are". I was stressed, until we went to court, divorced from there.

When marital difficulties were unrelated to the child's condition they were often related to paternal infidelity. Marital conflict sometimes resulted in separation or divorce which, in turn, resulted in financial difficulty.

In addition to marital difficulties, parents sometimes experienced family conflict because of their family's failure to accept the child, hesitation to provide caregiving support, or because of the family's frustration with the child's problem behaviours. One mother who lived with her parents described the way the continuous family conflict and complaints about her child's behaviour were discouraging and left her feeling hopeless and overwhelmed. For example, in reference to one particular incident she reported:

> There was a time she would wake up at like 3 or 4 [am]. She would just be crying, making noise. [They would say] "this is not a place [for] crying like it's a clinic". Saying those things - discouraging you -where you can think "Where can I go so that I can have peace". You can even have food on your table and you can't eat, thinking, "where can I go… with this child so that I can have free mind with her?"

Two mothers reported that their child's problem behaviours contributed to the conflict, as the family would become frustrated with the child and, sometimes, with the parent, as a result. For mothers who felt that the child was loved and accepted by the family, the child's problem behaviour may still cause momentary frustration, but the mothers also described reconciliation or continued love between the child and the other family members. Parents who felt that their child was rejected by their family experienced this as deeply painful. These mothers often reported anxiety related to what would happen to their child if they were no longer around to care for them. In the words of one mother:

> I just sit and think when my other sibling's children come my mom is able to welcome them. She's happy with them. But my mom has never put my daughter on her back. Not even getting her to put her on her lap – no. she has no time for her. but with my sisters she has her whole time … So I've been asking myself - I've even reached this extent of saying "why is this child being abandoned like this when I'm alive? What if I'm dead? who's going to look after her?"

Stigma

Eight mothers reported that they or their child received negative treatment or discrimination from others. For example, some mothers reported that neighbourhood children would not play with the child, sometimes because the mothers of those typically developing children had instructed them to avoid the child with special needs. Parents believed that this stigma was borne of a lack of understanding about developmental disabilities. For example, one parent reported that some neighbourhood caregivers may fear their children interacting with her child because they believe that her child's condition is contagious. A few caregivers alluded to the fact that this stigma was furthered by the lack of exposure in the community at large to such conditions as many children with special needs are hidden away. In line with this, some of what was experienced as stigma seemed to result from curiosity of bystanders about the child's condition. Parents reported being stared at and asked probing questions. While some parents were able to respond to this by ignoring the stares and answering the questions, other caregivers reported that it negatively affected them and made them feel sad or embarrassed.

Having a child with special needs also resulted in the mothers feeling as though they were being judged, gossiped about, or treated negatively. Mothers reported receiving blame or being shamed for their child's condition. Again, these reactions were sometimes related to ignorance about such conditions as some caregivers reported that people blamed them due to believing the child had been bewitched, perhaps in reaction to some fault that the parent or the family had committed against someone else. Some mothers reported that the stigma resulted in their feeling hesitation to leave the home with their child. For example, one mother said:

> Initially I didn't want to go out with him. I thought it was too much pressure, and there are stares, and what if he throws a tantrum and people just look, and sometimes people will be like, "what a horrible mother", and things like that.

This mother reported that sometimes negative comments made about her parenting or her child's behaviour would cause her to become emotional and lash out at bystanders. However, on other occasions she was able to maintain her composure and explain her child's condition to these bystanders who sometimes apologised once they understood the situation.

One college-educated mother described her child's condition as a "touchy subject" and a "sensitive matter". She reported that she believed other friends and family members had noticed her child's challenges but were afraid to point them out to her. For those with whom she eventually shared the diagnosis she perceived a sense of relief as they realized that she, too, had noticed her own child's challenges. She and some other mothers who participated in the study reported being selective about whom to share their child's diagnosis with because of concern about being talked about or judged.

One mother reported responding to stigma by ensuring that others know how proud she is of her child despite the child's challenges. This mother described a conversation that she had with a bystander who noticed her child's condition this way:

> She said, "you always put your child on your back, why can't you let her walk?" I said, "she doesn't walk, she's a special child". Then she says, "okay, but don't you feel shy when you're with her?" I said, "no, I'm very proud of her. I introduce her to everyone, so she knows I'm very proud of her. I would never let her down".

Another mother noted that allowing the stigma to affect you would result in further stress, so caregivers were better off learning to ignore it:

> It's because of what people [say] about the children so that makes it very difficult because there [are] a lot of bad things actually. So if you take it in you have a problem. If you brush it off, and focus on the growth of the child, you will be fine. Because some [caregivers] take it in and carry it, so it makes a lot of challenges.

Some mothers reported wanting to ignore the stigma but shared that, no matter how much they tried to do so, it still affected them. One parent reported disappointment in this, saying, "I thought I would be stronger now against it".

The stigma experienced by caregivers was also sometimes reported as a factor that resulted in fathers abandoning the family. A few caregivers reported hearing or witnessing situations in which other children with special needs in the community were neglected by both caregivers, often resulting in the deaths of those children. Such stories seemed to be experienced by mothers as warnings of what would happen if they allowed their treatment of their own children to be influenced by stigma.

Other Life Stressors

In addition to the topics covered above, mothers reported other miscellaneous sources of stress; including, neighbourhood safety concerns or concerns about the threat of theft due to their living conditions. Two caregivers reported being HIV positive and one reported having to care for an HIV positive spouse. This resulted in additional challenges related to health and physical well-being as well as the experience of stigma related to HIV. Finally, some caregivers described stress related to the burden of having to care for other family members or having a newborn or younger child in the home who also needed support. A few parents reported having to take in a number of dependents due to those extended family members becoming orphaned or their caregivers not being able to care for them due to financial difficulties. In terms of other children in the home, it was not surprising that having children older than the child with special needs was often experienced as relieving parent stress, whereas having children younger than the child with special needs sometimes resulted in greater stress.

Resources

Mothers in this study reported resources that may contribute to reductions in stress in this population and allow caregivers of children with DD to manage challenges more effectively. These resources can be considered to fall into two main categories: an individual's personal resources, including coping strategies, and their family system resources.

Individual Resources

Parents described a number of individual resources as helpful for raising a child with DD, including resourcefulness, self-efficacy, interest in learning, organization and planning skills, and social skills.

Four mothers reported that being resourceful helped them to find ways to address the many challenges that they experienced. For example, one mother described using a soup thickener to thicken water so that her daughter wouldn’t choke on it. Similarly, a few mothers reported focusing what free time they had on gardening so that they would always have vegetables to eat, even when their finances were limited. For these caregivers, findings solutions to these problems brought them pride and increased their self-confidence. Related to this idea was the parent’s openness to seeking advice from others or trying new ways of solving problems, which a few caregivers described as a personal resource.

Five mothers reported feeling confidence in their ability to support their child and meet his or her needs. Some caregivers described this confidence as changing from day to day, however. For example, one mother shared:

> Sometimes I feel like “yeah”, like I am ready, like I can do this, or I can do that. Then there are other times when I am just taken aback by certain situations and I feel like maybe I am not there yet.

Indeed, the mothers reported that their confidence grew over time, as they learned more about their child’s condition, and as they began to see their children progressing and gaining skills the child had previously struggled with.

A few mothers described their desire or interest in learning and acquiring new skills as being beneficial. As caregivers were faced with an overwhelming amount of new information and new challenges with their children, having an interest in learning and a desire to understand new things, pushed these caregivers to continue to ask questions and seek out new sources of information until they felt confident in their understanding.

Five mothers reported the necessity of being proactive, anticipating challenges based on prior experience with the child or with the systems with which they interacted, and finding ways to curtail future problems before they began. Similarly, one parent described herself as overly cautious, which led her to ensure that she was well-prepared. Some mothers also described the importance of learning to speak up and be open about their need for support and the challenges they are facing, in order to advocate for their child. One mother said, “I told myself ‘look, this thing is not going anywhere and if I don’t show the world or speak up for my child, nobody else is going to do that’,".

One mother reported that her ability to multi-task has helped her immensely to manage the multitude of tasks she needs to complete for her son, without becoming overwhelmed. Similarly, many mothers alluded to their willingness and ability to work tirelessly in order to provide their children with the things they needed. Parents were inspired to push themselves in order to be able to meet their children’s needs as much as possible. Additionally, being able to prioritize tasks when not everything can get done was described as a personal strength.

One parent described the way in which her social personality made it easier to both gather information for her own child, and also to help other caregivers. Indeed, although other parents did not directly refer to their own social skills, the importance of forming bonds with other mothers of children with DD was evident in many of the interviews and having an outgoing personality or being able to easily form bonds with others is likely a valuable personal resource.

Coping Strategies. Parents described a range of different coping strategies. The most commonly reported strategies were acceptance and religious practice (both of which were discussed by ten mothers); however, caregivers also endorsed positive reframing, active coping, substance use, self-distraction, and seeking support from others.

Two thirds of parents who participated in the study referenced the importance of acceptance in helping them to cope. Some factors that mothers described as helping them find acceptance included learning that it was not their fault, having faith in God, meeting other caregivers of children with DD, and seeing how many other children there were with DD. Parents reported that once they accepted the child's condition, things became easier for them. Parents reported that acceptance made them feel stronger and find happiness with their children. One mother described it this way:

> The doctor also gave me hope to say, "sometimes he can walk but if it's not God's wish then [he] will be moving in the wheelchair, you will be able to get your own chair, one way or another." So that way I was able to accept and just told myself, "I need to accept for my child to grow and for other people to help me because if you don't accept how will other people help you. Because you will be upset all the time".

Acceptance seemed to be interpreted differently by different mothers. For some, accepting their child's condition led them to learn more about it and be more proactive in learning how to promote the best outcomes for the child. Conversely, for other mothers, accepting their child's condition led to behavioural disengagement. For these mothers, accepting the child's condition and accepting that the child's condition would never go away meant there was no use in trying as nothing would change. These mothers instead focused their attention on trying to maintain inner peace and comfort in the face of any challenges they encountered. One mother reflected on this conflict about what "acceptance" really means by reflecting on a time she heard someone who was active in the DD community admitting that they sometimes wished their child's disability would just "go away":

> According to the standards they'll say "she has accepted" but then I feel like from that [statement she made] I feel like this is more [like] tolerance and how [can I make the best out] of the situation because it's not going anywhere … so if that is what acceptance is then yeah.

Religious practice was found to be beneficial as it helped caregivers to make meaning out of their difficult situation and to feel as though there was a larger plan for their lives. The caregivers reported feeling a sense of peace when they attended church services, read the bible, prayed, or listened to religious music. Parents described religious music and church services as “uplifting” and reported feeling renewed or comforted by them. Parents also tended to describe relying on their faith when they felt helpless or hopeless about their situation. Some mothers reported that their faith in God, their belief that their child was a blessing from God, and their belief that God had given them the child for a reason, helped them remain strong when faced with stigma. For example, one mother described telling her husband to respond to the stigma he received from his friends saying, “no this is the making of God … you don’t choose what you are going to give birth to, it is only God [who] gives you … whatever you receive and look after”. There was some diversity in the way parents used religious practices, such as prayer, to cope. For example, some mothers focused on praying that their child or their situation would change, while others focused on praying for virtues such as strength and compassion for the child.

Two mothers alluded to the value of being able to focus on the positives and maintain hope that they would be alright. One parent reported feeling as though focusing on negatives was draining, so she tried to “snap out of it” and focus on the positives in order to remain energized. Sometimes they were able to maintain positivity by having faith in God and trusting that he would support them. Mothers also reported that receiving words of encouragement from special education teachers and other professionals helped them to remain encouraged. Similarly, seeing other individuals who had special needs but were perceived to be doing “well” helped mothers maintain hope that they and their child would also be alright.

Focusing on positives, or reframing the way they perceived their situation, also helped mothers empathize with their children, express love for their children when times are difficult, and find ways to connect with their child. Parents alluded to achieving this positive reframing through methods such as prayer, treating their children as they would treat “normal children”, or obtaining education on the child’s condition.

A few mothers reported seeking distraction from their problems by sleeping or watching television. Others reported that taking walks when they had a lot on their mind was beneficial. Mothers reported that, although the problem remained after the walk, these walks sometimes helped them relax or provided some distraction. A few mothers endorsed keeping busy with housework and other such tasks rather than focusing on what sometimes felt like insurmountable problems. These mothers tried to stay focused on the concrete tasks that they could accomplish. One mother endorsed using alcohol to cope. She reported doing so in an effort to help herself feel more positive about things, thereby helping her to also be more cheerful in her interactions with her child.

Finally, six parents endorsed actively seeking out support or encouragement from others as beneficial. The impact of social support is described in more detail in the support section of the results.

Family System Resources

Eleven parents referenced the impact that their family had on their experience of raising their child. One significant way in which family was found to be beneficial was through the provision of childcare. Mothers described the relief they experienced as a result of family members helping them to care for the child. Receiving childcare allowed mothers to maintain employment outside the home or find other ways to spend their time in ways that could benefit the child or the larger family. Being able to get respite from caring for the child also provided time for some caregivers to relax or allowed some caregivers to participate in self-care activities, such as spending time with their friends. In addition to childcare, family members also helped caregivers by providing emotional support or encouragement. Three mothers reported that family and friends reminded them to love and treasure their child, which helped them maintain a positive connection with their child in times of stress. Additionally, family members provided support by helping provide instrumental care for the child or assisting with teaching the child (e.g., reading and writing).

A few mothers, however, reported not having family nearby or not being supported by their family. For these caregivers the absence of family support was felt deeply. These caregivers described feeling lonely and having nobody. One single mother of a child with cerebral palsy said sadly:

> Losing your mom and dad and you have no one we can say that “if this happens whom will I run to? … Maybe if I had a sister or a brother – “. I don’t really know what they are saying or if they are really concerned to visit me once in a while - and I’m not asking for anything, just a visit once in a while that was - at least that they care that they are concerned. But no one - January to December I’m just alone with a child like this”.

For women who had family nearby but were not supported, reasons included the family’s failure to accept the child and the family having their own issues to worry about. For some families, failure to accept the child’s condition was related to sadness or concern about the parent and how they would manage. Some mothers reported that their family found it easier to accept the child when they were not the first child in the family who had been born with a DD. Single caregivers who had no family support struggled to find or maintain employment and therefore experienced significant financial difficulties. Some of these caregivers reported seeking financial support from extended family members but few caregivers endorsed receiving such financial support. Parents who did not have family support relied on the support they received from other caregivers of children with DD.

More than half of the participants reported marital difficulties; however, a handful of mothers reported having a very supportive husband. In some cases, the biological father of the child accepted the child’s condition and was supportive while in other situations women were able to remarry men who accepted the child. Some fathers simply supported through the provision of financial support while, in other couples, women reported that the emotional support they received from their husbands was important as well. Finally, a few fathers were even more involved and helped the mothers physically care for the child as well. For example, a mother of four with an infant described her husband and oldest daughter helping out in this way:

> Having four children and taking care of them at once is not really an easy path for me, but I tried... Because I would find time and sit down with her and do one or two things but for now I am really really not been able to sit down and start – or maybe find time to teach her. But the sister and her father find some time for them, like reading stories for them and the sister will bring a picture and paint and do a few words on an alphabetical form - they try to do that at least once in a week.

Supports

Women in this study endorsed receiving both emotional and instrumental support from several sources; including friends, neighbours, other caregivers, religious communities, NGOs, schools, hospitals, and other government sources. Parents who did receive this support described it as helpful, while other mothers felt a notable absence of support from the aforementioned sources and reported that having such support would make a significant difference in their lives.

Informal Supports

The most frequently endorsed source of informal support was the other mothers who had children with DD. For many mothers this community of other parents who had children with DD became their friends. These mothers provided childcare for one another when needed, provided emotional support and practical advice, and shared valuable information and resources. Women found that talking to other mothers of children with similar needs to their own, not only lead to increased knowledge, but also increased confidence in their ability to care for their children. Additionally, women also felt more positively about themselves when they were able to help other mothers. In the words of one parent:

> Women – we have to be supportive. So that … we make groups, we discuss what the way forward [can be], on how we can keep these children with disabilities, our lives … Yes, we have to come together and give each other ideas on what we can do.

Overall, mothers found that coming together regularly, sharing their experiences with one another, and offering and receiving advice made everyone stronger. Even when conversations or interactions with others were not focused on resolving the issues that were the source of the parent's stress, being around others provided distraction that helped mothers feel "refreshed".

While two caregivers reported receiving continued emotional support from friendships they had established prior to having a child with DD, several mothers also referenced the ways in which pre-existing friendships changed after the birth of their child with DD. For example, two women reported that their friends grew more distant because they had less time to spend with their friends. One woman also reported feeling discouraged when she spoke to her friends as they would not be able to help her and would talk about how big her problems were. For example, she shared the following:

> My friends - some they say "no, we will come do anything. You have that problem. You can't go anywhere. You can't work. You can't do anything" … They say, "that problem is very big. Ay!" So sometimes I feel discouraged.

Religious communities were also described as a significant source of support by four mothers. Some women described ministers, priests, or other members of their religious community providing words of encouragement and going out of their way to check on the parent and ensure their well-being. Mothers found it helpful when members of their religious community reminded them to pray about the challenges they were experiencing or provided advice about the challenges they were facing.

There was variability in how helpful women in the study reported their neighbours to be; however, a few mothers reported having supportive neighbours who expressed empathy for the child, provided words of encouragement to the parent, and two caregivers even described neighbours providing respite to the child. For caregivers whose children were prone to running away, neighbours were often instrumental in helping keep the child safe or helping caregivers to locate the child when he or she could not be found. Caregivers who did not live in supportive communities were often reminded of this fact as they frequently heard disparaging words used to describe their child or saw the negative looks directed to their child.

Formal Supports

Formal supports accessed by mothers in this study included schools for children with special needs, mainstream schools, hospitals, and NGOs.

When mothers described the way they felt that the government had provided support for them and their child, many referenced the provision of government-funded special schools. In particular, caregivers valued the special education teachers, whom they described as going above and beyond their role to support caregivers at home and in their community. For example, some mothers described teachers approaching them, asking them if their child was in school, and providing them with information about the special school. Special education teachers not only educated the children but frequently also provided caregivers with information about their children’s conditions and helped them find other services that may be of use to them. The different special schools were diverse and differed in their approaches to educating the children. Unfortunately, for some caregivers in some schools, it seemed as though the education provided at school was not felt to be at the appropriate level for their child or was not found to be useful. As a result, some mothers stopped taking their child to school and focused, instead, on physical interventions. When asked what they would find helpful, a few women referenced a desire for more vocational training opportunities for their children. In addition to not finding the education useful, some caregivers did not take their children to school because they faced instrumental barriers to enrolling their child in special schools, such as lack of transportation.

Mothers who attempted to enroll their children in mainstream schools experienced significant barriers. All of the mothers who attempted to enroll their children in mainstream schools reported being told, by at least school, that the school could not accommodate the child's needs. Parents described this as a source of stress and the two participants who were able to eventually find a mainstream school that was able to support their child described this as a significant relief. Both of these women described challenges in obtaining an appropriate diagnosis for their child because the child's DD did not become apparent until the children entered the school system and began to struggle to learn. For both of these mothers, the mainstream schools they found that were able to accommodate their children were private schools and not government-funded schools. One of these mothers did attempt to enroll her child in a special school but, because her child did not have a formal diagnosis, it became a lengthy and difficult process for her to do so. This mother suggested that the difficulties some parents faced in enrolling their children in school lead many of them to keep their children at home instead. She described feeling that there was a need for mainstream schools to have some training or support in behavioural interventions or other programs for children with special needs so that caregivers did not have to struggle to obtain some level of support for their children and so that those children would acquire some valuable and practical skills. She shared her feelings this way:

> I feel that [if] we had a place that the schools can be more – adopting the children like, the way [child] is, and if they would accept her and try by all means to advise parents what to do and maybe what to bring so that we can also help children like [child] to be in school. Because if the children learn maybe certain behaviours can be trained... If they were in school they would be able to do anything, but because of procedures like the ones I mentioned of going there and there [i.e., parents having difficulty obtaining a diagnosis for their child] - a lot of parents would

> not manage that. So, in the long run, you find that they just let the child be without any help and that is a negative influence on the child. Because children, for example like [child], if they grow up without any help or training they tend to become violent because of the frustration and the lack of care that they need.

Mothers reported receiving support from hospitals; however, many described it as challenging to receive consistent services in the government-funded clinics and the type of care their child received seemed to depend on which doctor was working on a particular day. For example, one parent reported having this experience with her son:

> I took him to [hospital] and they say, “he’s got symptoms of a seizure”. They started giving him medicine for epilepsy. Then after taking the medicine for 3 … 4 months the other doctor asked me “how many times a day does he have seizures?” Then I said, “no I have never seen him doing that”. Then the doctor said, “no, stop … giving him the medicine”. That’s how I stopped. Then we took him to [NGO] … then the doctors came … they said “[child’s name] has autism”. Yeah, so this is when he started going to school. Never gave him any medicine [again].

Despite some negative experiences reported by parents, government-funded clinics were often the first point of contact for caregivers and played an instrumental role in directing caregivers to other useful services such as physiotherapy and special education programs. Many mothers reported having positive experiences with some clinicians; describing situations in which clinicians counselled them, instilled hope, and provided them with useful information. For example, mothers described the lack of familiarity with their child’s diagnosis as frightening; however, they reported that their fears were lessened when physicians were able to explain the child’s needs to them in lay language, when physicians reassured them that the child would make progress with intervention, and that they would learn to adapt to the needs of the child.

One mother reported noticing an improvement in care after switching from a government-funded clinic to a private hospital. Her new physician was proactive in providing her with resources to support her and her child and went out of her way to be supportive:

> That doctor got my number and then [she] was like constantly calling me, [asking] how the child is, how I'm coping up. Yeah and then she would invite me to attend workshops about children like my daughter's condition – CP – to learn more. Yeah, so it helped.

Half of caregivers who participated in this study reported receiving support from an NGO for children with special needs. The NGO helped families in a multitude of ways, including providing caregivers with training on how to implement interventions with their children at home, financial support, food, opportunities to attend workshops or receive more in-depth training about their children's conditions, and occasionally flying in medical professionals to diagnose children. Parents described the education as beneficial and reported seeing improvements in their children as a result of the interventions. Parents were also appreciative of the financial and food incentives but, unfortunately, stated that it was still not enough to meet their needs. This was especially true for single caregivers or other families struggling to secure consistent employment. Parents who had participated in workshops in the past found these to be extremely helpful and one parent described feeling as though many caregivers like herself would benefit from informative workshops even if the need was not evident. She described feeling as though some families may appear to be functioning relatively well on the outside but may still not be fully supportive of the child or of one another.

In addition to the programs described above, mothers described occupational therapy programs, physiotherapy programs, and a service providing free wheelchairs as helpful. One woman described being a part of a WhatsApp forum that had caregivers of children with DD as well as some professionals. This forum was described as extremely helpful.

Overall, when asked, a few of the parents reported a need for either financial assistance from the government, or the means by which they could secure their own income (e.g., transportation support, childcare). In addition to financial assistance, some mothers reported a need for government funding for more costly or specialized interventions (e.g., medication, surgeries). Mothers also reported wishing that the government would provide more information on DD to the public in order to support caregivers and in order to reduce social stigma. A few women reported feeling as though government supports for children with disabilities tended to focus on physical disabilities such as deafness and blindness, and neglected children with intellectual or other DD.

Outcomes

Mental Health

Thirteen mothers alluded to the impact that the ongoing stress in their lives had on their mental health. One single parent of a visually impaired child talked about the importance of having a “free mind” and reported feeling as though her mental distress prevented her from caring for her child to the best of her ability. A number of women in this study recognized their own unhappiness, stress, and overall mental state as having an effect on their child’s mood and health. One mother described it by saying, “what I just noticed or realized is that whenever I’m going through hard times, even my baby’s health goes low … when I’m excited, she’s also happy … if I have faith in everything then she will be alright”. The anxiety was generally experienced as negative; however, some caregivers described the anxiety as being related to positive outcomes, such as driving them to be proactive in ensuring their child’s safety or well-being.

Three women described being affected by guilt and self blame as a result of their child’s condition. While some caregivers reported that this guilt was relieved when professionals or other caregivers assured them that their child’s condition was not their fault, some caregivers reported that they continued to feel guilt despite assurances from others. For example, one mother who reported significant marital strain that pre-existed the birth of her child shared:

> I used to think that way because of what I've been going through in the past, yes. So I thought "maybe 'cause I've been stressed too much, that's why: during the pregnancy, during birth. So maybe that is what affected her". But as time goes by people have been telling me "no, it's not what you think". But as for now it is still … I feel bad.

This guilt resulted from thoughts that perhaps they could have done something differently during the pregnancy to prevent the child from being born with a DD, from wishing that they could do something to reduce the child's suffering, or from concerns that they are not meeting the child's needs in one way or another. For example, one mother went on to share the guilt she felt when her daughter was not able to keep up with peers saying, "whereby her friends will want to stand and she will follow them. Then she will fail. Then she will look at me. I feel like I've done - I feel guilty".

A few mothers reported sadness because of having to give up on certain dreams (e.g., going back to school) or neglecting other areas of need in their lives because the child's needs took precedence. In a similar vein, some caregivers discussed having to adjust their expectations for their child and expressed sadness about their child's lost potential:

> I feel a bit short-changed because, like I said, my middle child – with him he's been discovering what his interest is or what … he can use his potential in … I don't know if there is a place like where [my other son] could go with all these things – sports … swimming … music, everything – and then just go and let him be exploring everything [to see] what catches his attention most.

Like other mothers in this study, this mother expressed a need for services (e.g., vocational programs or extra curricular activities) catered towards, or flexible enough to include children with special needs so that such children would also be able to develop interests and skills.

Positive Gain

Mothers also described experiencing positive outcomes as a result of having a child with DD. For example, caregivers felt that their child taught them things and that facing the challenges that they had to go through helped them to grow stronger. A few caregivers also described the situation as making their families stronger, feeling as though the adversity brought the family closer together, and reported feeling as though their family could handle any challenge. Parents also reported having greater patience and learning how to show love. For example, one mother said, "I must say it has been very challenging. But at the same time, I have learned a lot, learned a lot as a mother: how to be patient and at the same time show a lot of love". Three other parents described experiencing growth in maturity and described this as having a positive impact on themselves and their families. For example, one mother of four reported that her child's needs gave her perspective in the face of marital conflict, saying:

> I've grown in terms of mature growth ... Looking at how [child] has progressed and how far I've been involved in - gives me a lot of strength and courage even to do other things. And the family - it has brought us together because we are able to think before we make any drastic decisions in terms of the - if I have marital problems, I'm able to sit down and analyze the situation before I even make a big problem that'll affect the children.

Discussion

Overall, in the present study, I set out to examine the experiences of mothers of children with DD in Zambia, using the Perry Stress Model (2004) as a conceptual framework. Themes emerging from the semi-structured interviews spanned a range of issues across the domains of the model; including stressors, resources, supports, and outcomes. Some emergent themes were consistent with literature on the experiences of mothers of children with DD in other countries, while some seemed to be unique to the experiences of parents residing in Zambia.

Consistent with the literature, mothers in this study reported experiencing a range of stressors (e.g., Cantwell et al., 2014; Gallagher et al., 2010; Gupta, 2007). For example, mothers in this study reported that the increased demands of caring for their children, due to factors such as the child's problem behaviours or comorbid health conditions, resulted in increased stress.

Mothers in this sample also reported a number of challenges related to accessing information about their child's conditions. Parents reported having to rely on informal information sources, such as other parents of children with DD or the internet. Mothers in the study also reported challenges accessing relevant interventions and services for their children. Sometimes parents reported being unaware of whether certain services existed in Zambia, and other times parents reported not being able to access existing services due to financial barriers or transportation difficulties. The results of this study suggest that mothers are often unable to rely upon health professionals as a consistent source of information as these professionals are often understaffed and overworked, do not always have expertise or familiarity with DD, and there is a high rate of turnover which results in a lack of continuity of care for the child in question. Misinformation about the child's condition was not uncommon in this sample and it is possible that, in addition to challenges accessing information, stigma and lay societal beliefs about disability may further limit access to information.

Financial need was a significant concern for many parents, who reported that this was a barrier to accessing interventions for their child and limited their ability to provide for their child's needs. Even though research by Bonilla and colleagues (2017) and Hjelm et al. (2017) provides evidence of the potential that financial support programs have to reduce poverty and improve the lives of Zambian families of children with DD, mothers in this study did not report receiving government financial assistance. In the present study, poverty was a significant concern for single mothers and was even greater for single mothers who did not have family support. These mothers shouldered the burden of financial provision alone, but had difficulty finding employment as they also struggled to find childcare.

Marital conflict was another stressor reported by some parents in this study. A few mothers reported that the adversity they experienced as parents of children with DD brought the spouses closer together; however, several mothers in this study described their child's difficulties as negatively impacting their marriages. These results are consistent with research by Nyoni and Serpell (2012) on Zambian parents of children with autism spectrum disorders, many of whom reported that challenges related to raising a child with autism placed a strain on their marriages.

Research by Mwape and colleagues (2012) suggests that marital difficulties are a widespread issue among couples in Zambia, including those with typically developing children. For example, their study found that men commonly deserted women for other women during pregnancy or after childbirth. Women in the study felt that the desertion by partners was due to a change in women's focus when they became mothers: as women transferred their attention from partners to children. Such transfers of attention are likely more pronounced for mothers who have children with special needs. Mothers in this study also reported that some of the marital difficulty was related to stigma; with mothers feeling unhappy about the father's failure to accept the child's condition, and mothers reporting that fathers blamed them for the child's condition. Some mothers reported that failure to accept the child's condition and blaming mothers for the child's condition or behaviours also resulted in conflict or lack of support from their extended family. Overall, these accounts revealed that stigma and lack of understanding about DD resulted in marital and family conflict.

Mothers in the present study reported experiencing stigma from the general public as well, in the form of stares, social exclusion of the child, and negative comments from others. Mothers reported feeling that the stigma resulted from a lack of understanding and exposure to DD as such conditions are not spoken about openly in Zambia and many children with these conditions are hidden. These results are consistent with other research on DD in Zambia (e.g., Mung'omba, 2008; Nyoni & Serpell, 2012). Mckenzie et al. (2013) argue that promoting a greater understanding of DD from an African perspective and encouraging participation of individuals with DD in social, cultural, and religious community activities will go a long way towards alleviating stigma.

In order to deal with these stressors, mothers report drawing on a number of resources. For example, mothers described the importance of personal traits and skills such as resourcefulness, self confidence, multi-tasking skills, and social engagement skills. Additionally, many mothers described the use of various coping strategies in order to manage stress, including acceptance, religious practice, positive reframing, active coping, substance use, self-distraction or avoidance, and seeking support. These results are consistent with the literature on coping strategies used by African caregivers (e.g., Allen et al., 2014; Chukwu et al., 2019; Kimemia et al., 2011). Overall, the majority of respondents endorsed using acceptance and religious practices to cope. This finding is not surprising, given the importance of religion in Zambian culture (Mung'omba, 2008) and considering that religious communities and religious leaders were frequently endorsed as a significant source of support in the present study.

At the family system level, childcare was an important resource. Mothers who had older children or extended family members living in the home tended to rely on them for childcare and mothers who were alone, or those who had family members who were unwilling to mind the child, described this as a source of stress. For some mothers, family support in the form of childcare allowed them to maintain gainful employment which reduced financial instability. Similarly, for mothers who were married, the most notable way that fathers provided support was through their financial contributions, as mothers were often unable to maintain employment due to the demands of caring for the child. These results are consistent with research by Sadiki and Mashegoane (2019) on South African parents of children with intellectual disabilities and suggest that educating families and encouraging them to provide support to mothers has the potential to improve conditions for mothers.

Parents who participated in the study endorsed some formal supports that contributed to reducing their stress; however, a number of parents reported feeling as though the government-funded supports available to them were limited. Mothers expressed feeling as though government supports for disabilities tended to focus on physical disabilities such as deafness and blindness and that children with DD and their families "fell through the cracks". Additionally, formal supports that were potentially helpful, such as schools and hospitals, were difficult for some to access due to barriers such as lack of transportation. Additionally, barriers to accessing healthcare services also included costs associated with medication and surgeries. In interviews of Zambian caregivers of individuals with cerebral palsy, Chiluba and Moyo (2017) similarly found that parents complained that bringing the person with cerebral palsy to the hospital was very difficult financially and physically.

Of all the formal services described by parents, the support received from special education teachers was the most consistently described as positive and significant. These teachers went out of their way to support caregivers: even going as far as to visit parents at home or receive phone calls from parents after hours. Parents reported relying upon these teachers to get information about their child's condition and how best to support him or her. Conversely, parents tended to describe mainstream schools as being unable to meet the needs of children with DD. These results indicate that teachers or schools have the capacity to be a convenient resource for increasing access to information for parents of children with DD. Increasing access to education and educating teachers (including mainstream teachers) on DD may be an efficient way to ensure that families of children with DD have access to the information and educational supports they and their children need.

Several mothers in the present study also reported receiving support from hospitals; however, many complained that the quality of support they received was inconsistent and depended on the clinician whom they saw on a given day. Different clinicians demonstrated different levels of knowledge about DD and, even when clinicians had knowledge about DD, clinics were often so busy and overstaffed that the clinicians did not have the capacity to provide parents with a level of support to match their expressed need. Mothers reported that doctors were often too busy to take the time to explain their child's condition to them. These findings are similar to those of Nyoni and Serpell (2012) on Zambian parents of children with autism. In their study, parents complained about the difficulty of obtaining diagnoses and recommendations from clinicians, and many participants complained of conflicting reports amongst health professionals over diagnosis of the child's condition (Nyoni & Serpell, 2012). Despite some difficulties, the results of the present study also highlight the potential for clinicians to have a positive impact on the lives of these mothers. Some parents described the importance of counselling they received from some clinicians, talked about clinicians instilling hope, and were thankful for the useful information they provided. However, in order to increase the frequency of such positive interactions with healthcare professionals, some issues need to be addressed, including the challenges faced by healthcare providers that may limit their ability to provide support, and challenges parents face in accessing healthcare. Challenges faced by Zambian doctors are not overstated, as research suggests that they face a considerable amount of stress in the workplace related to factors such as a lack of resources to carry out the job, high workload, low level of reward, and long working hours (Menon et al., 2007). Physicians will therefore need to be better supported themselves, in order to be able to better support children with DD and their parents.

In light of the challenges many parents face in accessing information and support from formal, government-funded services, NGOs and informal support sources such as religious communities and other parents of children with DD, are instrumental reducing the gaps. For example, parents reported that NGOs provided some food assistance, and provided guidance and training for parents on how to implement interventions with their children. NGOs were also able to fly in physicians from the United States to diagnose a number of children and provided educational workshops to a limited number of parents. Other parents who also had children with DD were the most frequent source of support endorsed. These parents provided advice and emotional support to one another. Additionally, many mothers reported that the act of sharing experiences with one another made everyone in the group stronger. In some ways, this network of support performed some of the actions that a more robust community-based health program might provide if available. For example, when parents were aware of beneficial services in their community (e.g., free wheelchairs) they were able to share this information with mothers who might benefit.

Despite the significant stressors endorsed by parents in this study, both negative and positive outcomes were described. Poor mental health - in the form of anxiety, unhappiness, loneliness, guilt, and stress - was a significant outcome for many mothers. Mothers described these mental health concerns as related to rejection of their child by others, isolation of the child and of the parents themselves, and parents' concern for the future. Mothers also reported positive changes as a result of having a child with DD. For example, mothers reported that the experience helped them to grow or mature, increased their capacity for love or compassion, and gave parents perspective in the face of other challenges. Exploring ways to enhance parents' positive perceptions of their children with DD has the potential to improve parents' outlook on their lives and may promote positive mental health and resilience.

The present study had some limitations. It is important to note that all participants were urban-dwelling Zambians living in the capital city. Participants alluded to the fact that they had access to services that would not be available if they lived in other parts of the country. The needs of parents may therefore be even greater in other, especially more rural, parts of the country. Another limitation was that only English-speaking mothers were included in the present study and the sample was relatively small. As a result, it is unclear how well these results represent other mothers and it is unclear how broadly applicable the recommendations will be. Similarly, the sample may be biased in that, mothers who are willing to engage in research pertaining to their child with DD may be qualitatively different, and have different experiences and perceptions, than mothers who would not be willing to do so.

Despite some limitations this study has a number of strengths. This study was the first to broadly explore the experiences of Zambian mothers of children with DD across the domains of stressors, resources, supports, and outcomes (including positive outcomes that are rarely considered). The qualitative design was considered a strength as it allowed mothers to bring up topics or expand upon questions with information that would not otherwise have been examined. Further, this study highlighted issues that require further examination using other methodologies. Specifically, I felt it important to quantitatively examine which stressors, resources, and supports are correlated with and most predictive of positive or negative outcomes in Zambian parents of children with DD, as was explored in Study 2.

Study 2: Factors Related to Stress-Related Outcomes in Zambian Parents who have Children with Developmental Disabilities

Research has consistently documented greater levels of stress in parents of children with DD (e.g., Cantwell et al., 2014; Gallagher et al., 2010; Gupta, 2007); however, several factors have the potential to mediate the relationship between the experience of parenting a child with a DD and parent outcomes. These include child characteristics, such as the severity of the child's disability (Plant & Sanders, 2007); other life stressors, such as social stigma (Narullah, 2013); parent resources, such as resilience (Bitsika et al., 2013), self-efficacy (Minnes et al., 2015), and coping strategies (Minnes et al., 2015); informal support, such as social support (Cantwell et al., 2014); and formal support, such as healthcare services (Mitchell & Hauser-Cram, 2008). Experiences of parents of children with DD are not universal; therefore, to fully understand the stress experiences of parents of children with DD it is important to examine the way outcomes of parents are affected by the multitude of variables at play.

For parents of children with DD in Zambia, it is particularly important to understand the impact of their unique cultural and economic context, in addition to all the other variables listed above, on the outcomes they might experience. For example, a qualitative study by Chiluba and Moyo (2017) found that Zambian parents of children with cerebral palsy reported a need for more institutional-level support and expressed disappointment with a perceived lack of government assistance. High levels of poverty in Zambia provide a barrier to achieving equal treatment and welfare of individuals (Mung'omba, 2008) and Zambian children with DD still fail to access education at the same rates as typically developing children (Dawson et al., 2003). This lack of education and the reduced employability that results from a lack of education likely adds to the stress of parents who are often left with the prospect of having to continue to support their children indefinitely.

Zambian parents of children with DD may also face social costs which can increase parenting stress. Nyoni and Serpell (2012) found that many Zambian parents of children with autism reported increased marital conflict and strain on their interpersonal relationships. Social stigma is also a concern for many parents (Loeb et al., 2008). While some Zambian values contribute positively towards the acceptance of those with disability (e.g., the belief that every child is a gift from God), these values are not always practiced, and some communities are far less accepting than others (Zulu, 2016). In Zambia the presence of disability may be seen as the consequence of social–cultural and religious misfortunes directed to the family and may result in the individual with impairment being seen as "unclean" (Mung'omba, 2008). Research by Donald and colleagues (2015) suggests that high levels of social stigma experienced by parents in Zambia can prevent them from reaching out for support or accessing services. Additionally, social stigma or shame may prevent extended family members from helping care for the child.

Outcomes of parents are of particular importance as experiencing greater levels of stress may cause them to be less effective at caring for their children. It is therefore important that we consider parent health and well-being as parent stress not only affects them but has the potential to affect their capacity to support their children as well.

Study Objectives

Existing research has established the negative impact that parenting stress can have on the outcomes of parents and children (e.g., Cantwell et al., 2014; Gallagher et al., 2014; Lovell et al., 2014); however, few studies have examined the experiences of parents of children with DD in Zambia, and no studies were found specifically examining parenting stress in Zambian parents of children with DD. The few studies that do exist examining the experiences of Zambian parents of children with DD tend to focus on the difficulties parents report, with no studies examining the positive impact that Zambian parents of children with DD may experience, as well as the factors that may promote more positive outcomes among these parents.

As was done in Study 1, the current study used the Perry (2004) stress model as a theoretical framework to engage in a multifaceted exploration of the experiences of these parents. The primary goal of the present study was to explore the stressors, resources, supports, and outcomes reported by urban-dwelling Zambian parents, using quantitative research methodology. The second goal of the study was to determine which stressors, resources, and supports are significantly predictive of outcomes in this sample.

Method

A researcher-administered questionnaire (Appendix E), consisting of measures used to assess each of the eight components of the Perry (2004) model, was completed with caregivers (mostly women) of children with DD residing in Lusaka, Zambia. Eligibility for participation in the study included being a primary caregiver of at least one child with DD (as identified by the respondent) below the age of 22. In order to have a representative sample, participants were not required to be fluent in English, although many were. This was different from the English fluency requirement for Study 1. For participants who were not fluent in English, I or a research assistant translated items into one of the two major local languages (iciBemba or iciNyanja).

Participants

Participants were 76 Zambian caregivers who self-identified as having a child with a DD. All participants of Study 1 (*n* = 15, 19.7%) participated in the present study as well as 61 additional participants. Most of the participants were women (94%, *n* = 71) and most were biological parents to the child (*n* = 66; 88.0%). Respondents who were not the biological parents had various relationships with the child in question, although all respondents took on a significant portion of the caregiving role.

Some respondents were grandparents (*n* = 5; 6.7%), one was a step-parent, one was an adoptive parent, one was an older sister, and another respondent was the child's aunt who the child lived with on most days. Respondents' ages ranged from 18 to 75 (*M* = 37.59, *SD* = 11.15). Most participants were married (*n* = 46; 61.3%).

Most respondents (*n* = 49; 64.5%) described themselves as being fluent in English; however, many parents who did not endorse being fluent in English were still able to converse in English. Most respondents (*n* = 52; 70.3%) were unemployed and 33.8% (*n* = 23) of respondents reported that they had reduced their hours or work in order to care for their child. Education levels were varied and ranged from below 7th grade to graduate level education.

More than half of the children whose parents participated in the study were male (*n* = 43; 56.6%) and their ages ranged from 1 to 20 years, with a mean age of 10.65 years (*SD* = 4.68). Due to the difficulty of obtaining clear diagnoses, many parents were unsure of their child's diagnosis and I was unable to confirm the diagnoses of many of the children. As this lack of diagnostic clarity was so widespread and as I assumed that it disproportionately affected low-income and disadvantaged families, confirmation of diagnosis was not used as an inclusion criterion for this study. Nevertheless, all parents who participated in this study were either able to provide a formal diagnostic label for their child's condition or reported that their child had at least one physical disability from a list provided as part of the questionnaire (see Results).

Procedures

Questionnaires were completed between August 2017 and October 2017. Informed written consent was obtained prior to each interview (see Appendix B). All but one of the questionnaires were completed in person with either me or a research assistant (typically both were present together) who was able to provide clarification if any questionnaire items were unclear to the participant. Clarification of items either involved rephrasing or clarifying the wording of items in English, or providing an on-the-spot translation of the item into a local language in which the respondent was more fluent. The remaining questionnaire was completed online in English. The questionnaires that were completed in person were either completed in the home of the participant, the home of the participant's friend, or in a classroom at a local school. When completing the questionnaires, we used ratings from only one parent; however, the respondent's spouse, other children, or extended family members were sometimes present in the room in which the questionnaire was being conducted. The child with the disability was also often present. Respondents were always provided with the option to complete the questionnaire at a different time or in a different location. Completion time for the questionnaires ranged from approximately 45 minutes to 90 minutes in length.

Participants were recruited through purposive and snowball sampling. Specifically, I personally contacted schools, hospitals, and non-governmental organizations that provided specialized services for children with special needs. The organizations that agreed to circulate information about the study were then provided with information letters (Appendix B) to circulate to the parents. Additionally, some organizations had representatives (e.g., teachers) act as intermediaries to connect interested parents with me or a research assistant. Parents who participated in the study were then asked to share information about the study with any other parents who they knew who might be interested in participating as well. All participants received an honorarium of approximately $30 (provided in local currency) for participating in the study.

Measures

A single questionnaire was constructed that included various standardized and researcher-developed questions (Appendix E). Questionnaire measures listed below are organized according to which components of the Perry Stress Model they are designed to reflect.

Outcomes

The Friedrich short form of the Questionnaire on Resources and Stress (QRS–F; Friedrich et al., 1983), was used to measure stress experienced by families of children with disabilities. Similar to the approach used by other researchers (e.g., Cianfaglione et al., 2017; Hastings et al., 2005; Lloyd & Hastings, 2009), only the 20 items in the Parent and Family Problems subscale were administered. These 20 items measured negative impact of the child with DD on the parents. Parents were required to indicate whether a statement was True or False for their situation. Some items on the scale were negatively worded (e.g., "I get almost too tired to enjoy myself") while others were positively worded (e.g., “I can go visit with friends whenever I want”). Negatively worded items received a score of 1 if the parent endorsed the item as True and received a score of 0 if the parent endorsed the item as false. Positively worded items were reverse scored. Consequently, a higher total score, obtained by adding individual item scores, was reflective of higher levels of stress reported by mothers. The QRS-F demonstrates a good internal consistency reliability of .93 for the full scale (Friedrich et al., 1983) and ranging from .77 to .85 for the subscales (Osborne et al., 2008). The Parent and Family Problems subscale demonstrated good internal consistency in the present sample (α = .89).

Positive gain, or the perceived benefits of raising a child with DD (e.g., personal growth, learning new skills), was measured using the Positive Gain Scale (PGS; Pit-ten Cate, 2003). Even when stressors are present, parents of children with DD still report positive gains associated with caring for the child with DD, suggesting that positive aspects of parental well-being are not necessarily compromised due to having a child with DD (Jess et al., 2017). Further, Hastings (2016) suggests that positive indicators of maternal well-being, such as positive gain, likely exist in parallel (and not necessarily in opposition to) indicators of poor mental health. The PGS is a 7-item parent-report measure of the degree to which they experience positive outcomes in the process of raising a child with a disability. An example item is “Since having this child, I feel I have grown as a person”. Items on the measure are rated on a 5-point Likert scale, with higher total scores indicating greater positive gain. The measure demonstrates good internal consistency in studies of parents of children with disabilities, with an alpha of .80 (MacDonald et al., 2010) and .87 (MacMullin et al., 2011). The PGS demonstrated acceptable internal consistency in the present sample (α = .63).

The Family Impact of Childhood Disability (FICD; Trute et al., 2007) was used as a measure of both negative and positive outcomes. FICD is a 20-item measure of parental appraisal of positive and negative impact of childhood disability on the family, with a 10-item positive impact score and a 10-item negative impact score. Parents were asked to respond to positive items (e.g., “Raising a disabled child has made life more meaningful for family members”) and negative items (e.g., "There has been an unwelcome disruption to normal family routines") on a 4-point Likert-type scale ranging from *Not at all* (1) to *A substantial degree* (4). Both the Positive (α = .81) and Negative (α = .89) Impact subscales demonstrate strong internal consistency (Trute et al., 2007). he 10-item positive impact scale of the FICD demonstrated poor internal consistency (α = .52) while the 10-item negative scale demonstrated strong internal consistency (α = .85).

The World Health Organization Quality of Life-BREF (WHOQOL-BREF; World Health Organization, 1997) was also used as a measure of both negative and positive outcomes. The WHOQOL-BREF was the result of efforts to develop an international cross-culturally compatible quality of life assessment instrument. The 26-item measure was developed collaboratively in a number of countries worldwide (including Zambia) and extensively field tested. It assesses quality of life across four domains: physical health, psychological health, social relationships, and environment. Items on the measure (e.g., “How much do you enjoy life?”) are rated on various 5-point Likert-type scales. For example, some items have response options ranging from *Not at all* (1) to *An extreme amount* (5) while others have response options ranging from *Very dissatisfied* (1) to *Very satisfied* (5). The measure demonstrated good internal consistency in the original study, with alpha’s ranging from .71 to .86 across domains (World Health

Organization, 1997). In the present sample, parent ratings of their quality of life on the physical health domain of the WHOQOL-BREF demonstrated good internal consistency (α = .77) as did ratings on the environment domain (α = .84). Ratings on the psychological domain (α = .67) and ratings on the social domain (α = .64) demonstrated acceptable internal consistency.

Parent mental health problems were measured using the Kessler 6-item Psychological Distress Scale (K6; Kessler et al., 2003). The K6 requires the parent to report the frequency of symptoms such as nervousness and hopelessness on a 5-point Likert scale (e.g., "During the past 4 weeks how much of the time did you feel so sad that nothing could cheer you up?"). The K6 demonstrated strong internal consistency in the pilot study (α = .89; Kessler, et al., 2002) and in the present sample (α = .84).

Stressors

Child Characteristics. Child diagnosis, mental health, and physical health were assessed using questions adapted from the GO4KIDDS Survey (see Appendix E; Perry & Weiss, 2009). The 6-item, 5-point Likert-type scale used to measure children's mental health demonstrated good internal consistency in the present sample (α = .75).

Parent's report of their child's adaptive skills and maladaptive behaviours were measured using the short form of the Scales of Independent Behavior - Revised (SIB-R; Bruininks et al., 1996). Both the adaptive (α = .93) and maladaptive (α = .93) indices of the SIB-R have demonstrated strong internal consistency in a previous study (Weiss et al., 2013). In the adaptive behaviour section, adaptive skills including Motor skills, Social Interaction and Communication skills, Personal Living skills and Community Living skills are measured, using 40 items such as "Stands alone and walks for at least 6 feet". Parents were asked to respond to these items on a 4-point Likert-type scale ranging from *Never or rarely* (0) to *Does very well* (3), based on how well the child can do each task completely without any help or supervision. Scores on the measure can be converted into an Adaptive Age Equivalent score, which was used to represent adaptive skills in the present study.

In the maladaptive section of the SIB-R, parents were asked to indicate if their child exhibits any of the eight categories of maladaptive behaviours (hurtful to self, hurtful to others, destructive to property, disruptive behaviour, unusual or repetitive habits, socially offensive behaviour, withdrawal or inattentive behaviour, and uncooperative behaviour). If a behaviour is present, parents were asked to rate the *frequency* of this behaviour on a 6-point Likert-type scale ranging from *Never* (0) to *One or more times an hour* (5), and the *severity* of this behaviour on a 5-point Likert-type scale ranging from *Not serious/not a problem* (0) to *Extremely serious/a critical problem* (4). Total scores on the General Maladaptive Index range from +10 (good) to -74 (extremely serious), with an average of 0 and standard deviation of 10. Lower or more negative scores indicate more serious levels of maladaptive behaviours.

Other Life Stressors. The influence of other life events outside of a direct parent-child relationship was measured using a combination of items from the Parenting Stress Index – Life Stress or LS scale (PSI, Abidin, 1995) and the GO4KIDDS survey (Perry & Weiss, 2009). The Life Stress scale of the PSI includes 19 items that provide an assessment of situational stressors that influence parenting stress. Parents are asked to indicate life stresses on the list that they have experienced during the last 12 months (e.g., “Loss of employment”). In addition, 10 items were added based on the GO4KIDDS survey and relate to stressful life events related to having a child with DD (Perry & Weiss, 2009). This list includes events such as “Experienced another difficult transition”, “Lost a good education assistant or teacher”, and “diagnosis of another child/family member with a disability” (Weiss et al., 2016).

The Stigma-by-Association measure is a 9-item questionnaire that was designed to measure the stigma experienced by family members of individuals with mental illness. In the original design, it allows parents to rate whether or not they have experienced stigma as a result of their child’s mental illness

(Sanden et al., 2015). For the purposes of this study the wording of the items was adapted slightly to refer to *disability*, rather than *mental illness*. Parents rate how strongly they identify with each of the 9 statements on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*) (Sanden et al., 2015). The Stigma by Association scale demonstrated strong internal consistency in the present sample (α = .93).

Due to the difficulties inherent to measuring socioeconomic status (SES) across cultures, several different measures were used. The Barratt Simplified Measure of Social Status (Barratt, 2006) was one method used to measure SES. It consists of items pertaining to education and current occupation. Ratings on each item provide a social status score that can range from 8 to 66 (Barratt, 2006). People who are unemployed receive a score of “0” on the measure. In two-parent families, the mean of the two parent scores was used. Some occupations that were common in the present sample (e.g., roadside sales, pastor) were not easily categorized according to the measure’s scoring key. There were also some career-labels (e.g., “business woman”) that were ubiquitous but provided limited information about the income the individual was generating or the security that their occupation afforded them. These professions were assigned a rating aligned with the category that was judged to most closely resemble the profession. Nevertheless, it was difficult to determine how meaningful these scores were.

Another method of measuring SES involved having participants indicate whether or not they own 15 household assets (e.g., bank account, computer, mobile phone). In this method household assets serve as a proxy for wealth and can be used to determine relative SES between groups. The 15 assets used in this study were identical to those used in research by Filmer and Pritchett (2001). This means of measuring SES has been found to be effective in multinational studies.

A final method for measuring SES involved the measurement of social capital using items from the questionnaire used in Wave 4 (2002) of the United Kingdom’s Department for Work and Pensions’ Families and Children Study (Phillips et al., 2003). Items required participants to rate a number of items in terms of whether they have access to an item, would like but cannot afford the item, or have no interest in the item. Items are extracted from several categories related to family well-being and social capital; including food/nutrition (7 items), clothing (7 items), durable goods (14 items), and social activities (6 items). Similar to the approach taken by Emerson and Hatton (2007), financial hardship was estimated by calculating the number of items that each family would like but cannot afford.

Resources

Parent Personal Resources. Parent self-efficacy was measured using the 12-item family domain of the Family Empowerment Scale (FES; Koren et al., 1992), which was designed to measure personal empowerment in families of children with disabilities. The scale requires parents to rate the degree to which they feel empowered to care for their child and manage difficulties that arise on a 5-point Likert-type scale. The family domain demonstrates strong internal consistency (α = .88) and test-retest reliability (*r* = .83). The scale demonstrated good internal consistency internal consistency (α = .84) in the present sample.

Carver's (1997) brief situational format of the Coping Orientations to Problems Experiences inventory (Brief COPE; Carver et al., 1989) was used to measure strategies used by parents to cope with stressors associated with raising their child with DD. Internal consistency for the measure is acceptable with most subtests demonstrating an α between .62 and .92. The mental disengagement subtest, however, demonstrated an α of .45. The Brief COPE was developed to measure 14 discrete coping strategies and is thus organized into 14 subscales, each containing two items (Carver et al., 1989). Parents are required to rate statements describing strategies that individuals might use to cope (e.g., “I've been turning to work or other activities to take my mind off things”) on a 4-point Likert-type scale with higher scores indicating more frequent use of that strategy.

The measure was developed to measure 14 discrete coping behaviours; however, factor analysis did not confirm this 14-factor structure in the original study (Carver et al., 1989). In subsequent studies, both the number of factors, and the items that load together, have varied (Tang et al., 2016). Some researchers have treated the original 14 subscales as individual factors, while other researchers have grouped the subscales based on theoretical justifications or based on the results of factor analyses (for a summary, see Krageloh, 2011). Due to this information, and as it was unclear what the factor structure of the measure would be in the present sample, a factor analysis was conducted to explore the factor structure of the COPE in the present sample so as to determine what scores to use.

Factor Analysis of the Brief COPE

Exploratory Principal Component Analyses (PCA) with Varimax rotations were conducted with two, three, and four component structures. The factor analysis was conducted at the subscale level, as was done by Carver and colleagues (1989) in the development of the original COPE questionnaire from which the Brief COPE was later derived. This method of factor analysis, termed individual extension analysis (Bernstein & Teng, 1989), has also been used in a number of other studies exploring the factor structure of the Brief COPE (e.g., Hastings et al., 2005; Lee & Liu, 2001; Zelikovsky et al., 2007). Subscales of the Brief COPE were included within a component if they met three basic criteria: (1) subscale loading on that component was greater than .50, (2) subscale loading on that component was positive, and (3) subscale loading on all other components was less than .50.

Overall, the four-component structure, accounting for 63.3% of the variance and, having 6 subscales with eigenvalues greater than 1, accounted for the most variance and had the most face validity. Factor loadings of the four-component analysis are presented in Table 1. Factor 1 included the Emotional Support, Instrumental Support, and Religion subscales. Factor 2 included the Denial, Behavioural Disengagement, and Self Blame subscales. Factor 3 included the Active Coping, Planning, and the Acceptance subscales. Factor 4 included the Positive Reframing and Venting subscales. The Humor, Self-Distraction, and Substance Use subscales did not load on any factors when using the above criteria. Factor 1 was named “Support Coping”, Factor 2 was named “Negative Coping”, Factor 3 was named “Active Coping”, and Factor 4 was named “Release Coping”.

Table 1

Factor Loadings of the Brief COPE

Brief COPE Subscale	Factor loading			
	Support Coping	Negative Coping	Active Coping	Release Coping
Active Coping	.11	-.08	**.70**	.45
Planning	-.10	.08	**.75**	-.04
Positive Reframing	.05	-.15	.03	**.71**
Acceptance	.16	.25	**.72**	-.18
Humor	.20	.59	-.06	.64
Religion	**.84**	-.02	.08	.04
Using Emotional Support	**.87**	.18	.16	.14
Using Instrumental Support	**.82**	.22	.06	-.19
Self-Distraction	.29	.09	.44	-.39
Denial	.15	**.79**	.07	.12
Venting	-.16	.13	-.03	**.69**
Substance Use	-.60	-.16	.45	.14
Behavioural Disengagement	-.02	**.66**	.03	-.34
Self-Blame	.18	**.69**	.15	.06

Note. N = 76. The extraction method was PCA with Varimax rotations. Factor loadings meeting the inclusion criteria are in bold.

The four factors were then examined for internal consistency using the individual items that made up the subscales, and not the subscale totals used in the factor analysis. Individual items that reduced the internal consistency of the factor were then dropped. Using this criterion, item 20 (“I've been accepting the reality of the fact that it has happened”) was dropped from Active Coping and item 21 (“I've been expressing my negative feelings”) was dropped from Release Coping. The final Support Coping factor (α = .70) demonstrated good internal consistency, as did Negative Coping (α = .76) and Active Coping was acceptable (α = .63). Release Coping demonstrated poor internal consistency (α = .50) and was therefore excluded from additional analyses. The final scores for each of the three factors used in subsequent analyses were calculated using the mean of the item scores included in that factor.

Family System Resources. Marital satisfaction was assessed using two items taken from the GO4KIDDS survey (see Appendix E; Perry & Weiss, 2009).

The four-item Compensating Experiences subscale of the Inventory for Family Protective Factors (Gardner et al., 2008) was used to measure family hardiness. For these four items, parents were asked to rate their perception of how their family experienced mastery within the context of raising their child with a disability on a 5-point Likert scale from *Not at all like my family* (1) to *Almost always like my family* (5).

Supports

The 18-item Family Support Scale (FSS; Dunst et al., 1984) was used to measure the availability and helpfulness of various informal and formal supports. Parents were asked to rate the helpfulness of these sources of support (e.g., parents, relatives, friends, professionals and services etc.) on a 5-point Likert scale from *Not at all helpful* (1) to *Extremely helpful* (5), or *Not available* (0). The FSS demonstrated good internal consistency in the present sample (α = .77). Parents' satisfaction with their child's school was rated using the School Satisfaction Scale: a 9-item scales designed to measure school satisfaction for parents of children with DD (Perry et al., 2019). The School Satisfaction Scale demonstrated excellent internal consistency (α = .93) in the original sample (Perry et al.,2019) and in the present study (α = .91). Lastly, parents were asked to respond to a number of other questions regarding their access to supports, adapted from the GO4KIDDS survey (see Appendix E; Perry & Weiss, 2009).

Data Analysis

Descriptive statistics were used to report the frequency with which each item was endorsed in the sample. Means and ranges were also reported, where relevant. Correlations were run to compare the strength of the relationship between the outcome variables and potential predictors, as well as the strength of relationships amongst the predictors themselves. Predictors were then excluded to reduce redundancy in the model and to conserve power. Criteria for including and excluding variables included statistical considerations, such as the psychometrics of the variable, and consideration of the themes that emerged in Study 1. Specific considerations for the inclusion or exclusion of each variable are outlined further in the text. Hierarchical regression analyses were then conducted with child variables, other life stressors, parent's personal resources, family system resources, informal social support, and formal support and services entered at separate steps as predictors of outcomes.

Results

Outcomes

In the present sample, parents endorsed a mean of 10.31 (*SD* = 5.26), on the QRS-F out of a possible 20 points, suggesting intermediate levels of stress. Scores on the measure ranged from 0 to 19 overall and were roughly bimodally distributed.

Parent ratings on the PGS were highly positively skewed indicating that parents had high perceived benefits of raising a child with DD. Specifically, 6 of 7 items on the scale had mean ratings greater than 4, on 5-point Likert-type scales. The scale's overall mean score in this sample was 4.29 (*SD* = 0.47).

Parent ratings of the positive impact of the child with DD on the family, measured using the FICD, were variable in the present sample (*M* = 3.31, *SD* = 0.38) but slightly positively skewed, indicating a more substantial positive impact. Conversely, ratings of the negative impact of the child were variable (*M* = 2.40, *SD* = 0.79) but slightly negatively skewed, indicating a slightly less substantial negative impact.

Quality of life ratings on the WHOQOL-BREF were standardized in the manner described in the manual (World Health Organization, 1997). Following standardization, parents' ratings of their overall quality of life were normally distributed with a mean score of 50.00 (*SD* = 29.64).

Parent ratings of their mental health difficulties on the K6 were variable but were slightly negatively skewed (i.e., skewed towards fewer mental health problems being endorsed), with parents endorsing an overall mean score of 1.23 (*SD* = 0.92) on a 5-point Likert-type scale with response options ranging from 0 to 4.

Stressors

Children whose caregivers participated in the study had various diagnoses, with many participants reporting multiple diagnoses. For some parents, it was unclear the degree to which their children had been formally diagnosed versus parents discerning the nature of their child's condition by comparing them to other children with special needs. When asked to select their child's primary diagnosis 21.3% (*n* = 16) of parents reported that their child had a diagnosis of cerebral palsy, 16.0% (*n* = 12) endorsed a diagnosis of autism (many of these parents also reported that their child suffered from seizures or had attention deficit/hyperactivity disorder), 17.3% (*n* = 13) endorsed a diagnosis of developmental disability/intellectual disability, 8.0% (*n* = 6) reported that their child had Down syndrome, 6.7% (*n* = 5) reported that their child suffered from seizures or had a diagnosis of epilepsy, and two parents reported that their child had hydrocephalus. Twenty-one parents were not able to classify their child into any of the above diagnoses. Unfortunately, there was little diagnostic clarity and many caregivers were unsure of the child's diagnosis or, when asked about their child's diagnosis, provided a response that was vague or not classifiable. For example, one parent reported that a healthcare worker told her that her child's brain had shrunk, one parent reported that they had been told that the child's brain cells were not well connected, another parent described her child's difficulties as "memory loss", and another parent reported that the child's difficulties were the result of witchcraft.

Parents were also provided with a list of various physical disabilities and challenges and asked to endorse any experienced by their child. Parents endorsed a number of challenges (see Table 2), with the most common being *problems using his/her hands*, *problems using his/her legs*, and *seizures*. Under the "other" category, parents described concerns such as frequent infections, needing frequent blood transfusions, and speech-related difficulties. Notably, all twenty-one parents who were not able to classify their child into one of the formal DD diagnostic categories above did report that their child had at least one physical disability.

Table 2

Children's Other Physical Disabilities

Life Stressors	%
Problems using his/her legs	56.1
Problems using his/her hands	67.7
Other Problems with motor control/coordination	32.3
Seizures	42.9
Major vision impairment	22.0
Major hearing impairment	12.0
Feeding or eating difficulties	21.8
Heart problems	4.2
Asthma or other respiratory disease	17.0
Physical dysmorphology	27.5

Parent ratings of their children's physical health varied, with 11.1% (n = 8) of caregivers describing their child as *very unhealthy*, 27.8% (n = 20) describing their child as *unhealthy*, 18.1% (n = 13) describing their child as *average*, 30.6% (n = 22) describing their child as *healthy*, and 12.5% (n = 9) describing the child as *very healthy*. By contrast, ratings of children's mental health had limited variability. Overall, when parents rated the frequency with which they observed symptoms of poor mental health in their children on a 5-point Likert-type scale (with higher ratings indicating a higher frequency at which symptoms of poor mental health are observed), overall ratings suggested that parents observed few mental health problems in their children (M = 1.52, SD = 0.62).

Parent ratings on the SIB-R were indicative of low levels of adaptive skills (SIB-R Age Equivalent score) for many children, with some variability (M = 48.59 months, SD = 43.31 months). Overall, fifty percent of participants described their child as functioning at or below the level of a three-year-old. Ratings of maladaptive behaviours (SIB-R General Maladaptive Index score) were indicative of moderate levels of problem behaviours (M = -7.48, SD = 11.54).

Parents endorsed experiencing a number of stressors over the past year, on the life stress scale of the Parenting Stress Index (see Table 3). Out of a possible 23 stressors, a mean of 3.02 life stressors were experienced by parents, on average (Range: 0 - 8, *SD* = 1.81). The most commonly experienced stressors were *housing problems*, the *death of an immediate family member* and the *serious illness of a close relative or friend*.

Table 3

Family Life Stressors Endorsed by Participants

Stressors	n(%)
Separation	*3*(3.9)
Divorce	*5*(6.6)
Marital reconciliation	*1*(1.3)
Marriage	*12*(15.8)
Pregnancy	*9*(11.8)
Other relative moved into the household	*18*(23.7)
Moved to a new location	*13*(17.1)
Promotion at work	*3*(3.9)
Began new job	*2*(2.6)
Trouble with superiors at work	7.9 (*6*)
Serious illness or injury	*11*(14.5)
Serious illness of close relative or friend	*22*(28.9)
Recent immigration	*0*(0)
Housing problems	*35*(46.1)
Legal problems	*0*(0)
Problems with police or other authority	*3*(3.9)
Death of immediate family member	*27*(35.5)
Death of close family friend	*14*(18.4)

Parents were also asked to endorse any stressful events that their child with DD may have experienced over the past year (see Table 4). Parents endorsed few stressors in the lives of their children, with the exception of *entering a new school*: a stressor endorsed by 26.3% (*n* = 20) of caregivers.

Parents endorsed experiencing variable levels of stigma as a result of their child's disability (*M* = 2.68, *SD* = 1.28), and parents provided a range of ratings on the 9 items, on 5-point Likert-type scale.

Table 4

Stressors Experienced by the Child with DD

Stressors	*n*(%)
Entered a new school	*20*(26.3)
Been suspended or expelled from school	*0*(0)
Transitioned to middle school	*1*(1.3)
Transitioned to high school	*0*(0)
Transitioned out of high school	*1*(1.3)
Experienced another difficult transition	*1*(1.3)
Had difficulties with teacher	*0*(0)
Lost a good educational assistant or teacher	*0*(0)
Lost a good paid caregiver	*3*(3.9)
Diagnosis of another child/family member with disability	*2*(2.6)

Social status scores on the Barratt were skewed towards lower social status ratings with 11.8% of the sample receiving a score of 0 which indicated that the respondent was unemployed and, if they were married, had an unemployed spouse. Scores ranged from 0 to 54 and were variable (*M* = 17.17, *SD* = 15.22).

When 15 household assets were used as a proxy for wealth, there was limited variability in the sample for many of the 15 items. For example, the vast majority of respondents owned a mattress, mobile phone, and TV. Conversely, few people owned a computer (*n* = 19; 25.0%) and only one person (1.3%) owned a sewing machine.

Finally, when we estimated financial hardship by calculating the number of items that parents reported needing but not being able to afford, similar to the approach taken by Emerson and Hatton (2007), responses were approximately normally distributed. On average, parents reported needing, but not being able to afford, 18.3 (*SD* = 7.36) items out of a total of 34 possible items. Scores ranged very widely from 0 to 34.

Table 5
Assets Owned by Participants

Assets	*n*(%)
Bank account	*32* (42.1)
Chair or bench	*64* (84.2)
Computer	*19* (25.0)
Cupboard	*52* (68.4)
Electricity	*66* (86.8)
Iron	*61* (80.3)
Kitchen	*43* (56.6)
Refrigerator	*52* (68.4)
Mattress	*75* (98.7)
Mobile Phone	*72* (94.7)
Radio	*48* (63.2)
Sewing Machine	*1* (1.3)
Sofa	*62* (81.6)
Table	*60* (78.9)
TV	*68* (89.5)
There are more than 2 people for every room in your home	*26* (34.2)

Resources

Parents generally reported high levels of Self-efficacy on the FES, with overall mean ratings falling at a 4.07 (*SD* = 0.55) on a 5-point Likert-type scale. The scale demonstrated strong internal consistency in the present sample (α = .84).

Using the three factor scores for the Brief COPE described above, scores on the Support Coping factor ranged from 1.67 to 4.00 (*M* = 3.19, *SD* = 0.50), scores on the Negative Coping factor ranged from 1.00 to 3.83 (*M* = 1.68, *SD* = 0.69), and scores on the Active Coping factor ranged from 2.00 to 4.00 (*M* = 3.27, *SD* = 0.53).

When parents were asked to rate how happy their marriage was on a 5-point Likert-type scale the results were heavily positively skewed with the vast majority of respondents rating their marriage as happy (53.2%) or very happy (38.3%). Only 2 respondents described their marriage as “mixed” (4.3%), only one person described their marriage as “unhappy” (2.1%), and only one person described their marriage as “very unhappy” (2.1%).

Parent ratings of family hardiness on the four-item Compensating Experiences subscale of the Inventory for Family Protective Factors were fairly normally distributed, with parents reporting a mean hardiness rating of 3.69 (*SD* = 0.84) on a 5-point Likert-type scale.

Supports

Parent ratings on the FSS were first coded into whether or not they were available to the respondent. The number of supports reportedly available to respondents ranged from 4 to 18 (*M* = 12.28, *SD* = 3.07). Other parents were the source of support most likely to be rated as available to respondents, and co-workers were the least likely to be rated as an available source of support. When a source of support was available to parents, they rated how helpful that source of support was to them on a 5-point Likert-type scale. Higher scores were indicative of the source being more helpful. On average, parents rated their spouses or partners as being the most helpful (*M* = 3.26, *SD* = 1.52), followed by professional helpers (*M* = 2.96, *SD* = 1.48), and the child's school or daycare (*M* = 2.72, *SD* = 1.64).

Table 6

Parent Ratings of Sources of Support on the FSS

Source of Support	Availability *n* (%)	Helpfulness M (*SD*)
My parents	*50* (65.8)	2.30 (*1.65*)
My spouse/partner's parents	*32* (42.1)	1.42 (*1.49*)
My relatives	*60* (78.9)	1.64 (*1.30*)
My spouse/partner's relatives	*36* (47.4)	1.02 (*1.02*)
Spouse or partner	*53* (69.7)	3.26 (*1.52*)
My friends	*66* (86.8)	1.41 (0.*94*)
My spouse/partner's friends	*40* (52.6)	1.05 (*1.11*)
My own children	*63* (82.9)	2.64 (*1.49*)
Other parents	*70* (92.1)	1.73 (0.*95*)
Co-workers	*23* (30.3)	.94 (*1.43*)
Parent groups	*43* (56.6)	1.21 (*1.26*)
Social groups/clubs	*43* (56.6)	1.27 (*1.40*)
Church or religious community/spiritual leader	*58* (76.3)	1.92 (*1.42*)
My family or child's physician	*43* (56.6)	1.69 (*1.54*)
Child's intervention program	*65* (85.5)	2.18 (*1.30*)
School/day-care centre (e.g., preschool, kindergarten)	*60* (78.9)	2.72 (*1.64*)

Professional helpers (social workers, therapists, teachers, etc.)	*65* (85.5)	2.96 (*1.48*)
Professional agencies (public health, social services, mental health, etc.)	*63* (82.9)	2.50 (*1.45*)

Parents were asked a number of questions related to medical care. When asked if they had a doctor whom the family could see regularly, 27.6% (*n* = 21) of respondents said “yes”. When parents were asked if they had a medical specialist who understood their child’s disability and was competent in caring for them 62.7% (*n* = 47) of parents said “yes”. Finally, when asked to rate their overall satisfaction with the healthcare that their child receives most parents reported that they were satisfied (*n* = 33; 49.3%) or very satisfied (*n* = 12; 17.9%). By contrast, 22.4% (*n* = 15) reported that they were unsure, 4.5% (*n* = 3) reported that they were dissatisfied, and 6.0% (*n* = 4) reported that they were very dissatisfied. When asked, 14.7% (*n* = 11) reported that they had sought support from a traditional healer for their child’s condition.

When school satisfaction was examined, parents tended to report high levels of satisfaction with mean overall school satisfaction ratings falling at a 3.98 (*SD* = 0.56) on a 5-point Likert-type scale. Scores ranged from 1.40 to 4.90 and were positively skewed.

Finally, parents were asked about other sources of support. When asked if there was a religious elder or leader who has been able to offer comfort or other support in response to their child’s condition 56.6% (*n* = 43) of parents said “yes”. When parents were asked if they had any friends or family members who are available to help take care of the child if the parent needs a break or extra support 70.7% (*n* = 53) of parents said “yes”. Finally, when parents were asked if they had access to professional services to provide temporary care for the child (e.g., nanny, babysitter) 23.0% (*n* = 17) of parents said “yes”. Of these parents, the majority (*n* = 10; 66.7%) reported receiving this respite care in their home.

Regression Analysis to Explore Predictors of Parental Outcomes

Hierarchical regressions were conducted to analyze which factors were predictive of parental outcomes in the present sample.

Selecting Variables to Include in the Regression

Due to the modest sample size, and in order to conserve power, only a limited number of variables could be included in the regressions. Therefore, prior to conducting the regression analyses, I selected a limited number of variables across the four domains of the Perry Stress Model (stressors, resources, supports, outcomes) and their subcategories. Selection of variables to include in the regression was based on various criteria, including considerations of which themes were most prominent for Zambian parents in Study 1, and the psychometrics of the measures in the present sample (i.e., reliability, range, distribution).

Outcomes. Positive Gain, Quality of Life, and Mental Health Problems were chosen as outcome measures. Quality of Life was measured using standardized scores from the WHOQOL-BREF item that required parents to provide an overall rating of their quality of life. Mental Health Difficulties was chosen as a negative outcome measure and was measured using parents' mean scores on the K6. Despite being heavily skewed, the PGS was selected over the FICD (positive subscale) as a positive outcome measure as it provided an estimate of positive outcome that was personal for the parent – whereas the QRS-F and FICD provide estimates of the impact of the child's DD on the broader family.

Stressors. Child Health, Adaptive Skills, Maladaptive Behaviour, Stigma, and Financial Need were selected as stressors. Due to the lack of clarity many parents had concerning their child's specific diagnosis, this variable was not included in the regression. Child Health was included in the regression as this was a significant concern for many parents. Child Health was measured using parent ratings on the single item that required parents to rate their child's overall health in comparison to other children the same age. The child's Adaptive Skills were included in the analysis as the child's dependency on the parents was a frequently reported concern. Adaptive Skills were measured using the age equivalent score on the SIB-R. Children's physical disabilities were a frequently reported concern; however, the Child Physical Disability variable was not included in the regression as the impact of this stressor was thought to be already better represented through the Child Health and Adaptive Skill variables. For example, the degree to which a child's problems using their legs or hands impacted their parent was likely captured in the adaptive skill item and the stress engendered by a child's heart problems or respiratory concerns was likely captured through the child health item. Maladaptive Behaviour was included in the regression as many parents in Study 1 discussed the impact of their child's problem behaviours on their relationships with others (e.g., neighbours, family). Maladaptive Behaviour was measured using the General Maladaptive Index score on the SIB-R. Stigma was included in the regression and was measured using mean scores on the Stigma By Association scale. Financial Need was similarly included in the regression and was measured using the financial hardship estimate approach used by Emerson and Hatton (2007). This measure was chosen over the other options for measuring SES as the data were the most normally distributed and the measure was judged to be the most meaningful and reliable estimate of SES in the present sample.

Supports. The total number of supports endorsed by parents on the FSS was chosen to represent Support in the regression model. Mean helpfulness ratings of each source of support were judged to be more arbitrary than the parent's endorsement of whether or not that source of support was available. School satisfaction was not included in the regression as parent interviews in Study 1 suggest there is variability in access to appropriate schooling and parents' expectations of their child's school. For example, through discussion with the parents it emerged that some parents attended "special needs schools" with their children that were focused on training parents to provide physiotherapy or speech therapy to their child at home. By contrast, other special needs schools focused on providing more academic instruction, at the level of the child (e.g., teaching the child to read). As a result, ratings on this item were judged to be less meaningful as there was significant variability in what types of instruction the various schools provided.

Resources. Self-efficacy, Active Coping style, Support Coping style, and Negative Coping style were selected as resources in the regression. Self-efficacy was included as many parents in Study 1 described how their own self-reliance and resourcefulness helped them manage challenges. Self-efficacy was measured using the mean score of parents' ratings on the family domain of the Family Empowerment Scale (Korenet al., 1992). Many parents in Study 1 also discussed various coping strategies, such as turning to religion or turning to others for support. As a result, coping was included in the regression. Spousal support was endorsed as a significant source of relief by some parents in Study 1, and marital difficulties or dissolution were reported as a source of stress for many parents in Study 1; however, marital satisfaction was not included in the regression as the item was heavily skewed and was not judged to meaningfully capture the experiences reported by parents in Study 1. Additionally, single parents did not respond to ratings of marital satisfaction, therefore if the item were included in the regression it would have had missing data for single parents. Family hardiness was excluded from the regression as the concept did not seem to emerge in the interviews in Study 1.

To summarize, three hierarchical regressions were run to measure the degree to which various stressors, resources, and supports account for variability in the three outcomes: Positive Gain, Quality of Life, and Mental Health Difficulties. The potential predictors examined were the same in all three regressions and included selected stressors, resources, and supports. Stressors included in the regression were Financial Need, Child Health, Adaptive Skills, Maladaptive Behaviour and Stigma. Support was measured using the total number of sources of support endorsed by parents. Finally, Resources included in the regression were Self-efficacy, Active Coping, Support Coping, and Negative Coping.

Table 7

Correlations among Variables

	Positive Gain	Quality of Life	Mental Health Problems	Financial Need	Child Health	Adap Skill	Maladap Beh	Stigma	Support	Self Eff	Active Coping	Support Coping
Financial Need	.09	-.53**	.51**	-								
Child Health	.11	.42**	-.39**	-.18	-							
Adap Skill	.09	.32**	-.43**	-.31**	.54**	-						
Maladap Beh	-.05	.10	-.12	-.12	.25*	.09	-					
Stigma	.03	-.24*	.46**	.30**	-.24*	-.31**	-.10	-				
Support	.00	.39**	-.10	-.08	.22*	.26*	.09	-.05	-			
Self Eff	.51**	.39**	-.34**	-.33**	.20*	.13	.10	-.25*	-.06	-		
Active Coping	.20	.18	-.13	-.11	.20*	.05	-.34**	.08	.11	.23*	-	
Support Coping	.14	-.03	-.02	.08	.01	.03	.01	.11	-.03	.21*	.28**	-
Negative Coping	.06	-.42**	.55**	.27*	-.35**	-.32**	.05	.43**	-.17	.03	-.08	.22*

Note. **p* < .05, ***p* < .01

Correlation Analysis

As a next step, prior to conducting the regression analyses, a correlation analysis was run to explore the relationships among the three outcome measures and the predictor variables that had been selected for the regressions (Table 7).

Predictors of Positive Gain

Correlations comparing the strength of the relationships between Positive Gain and potential predictors (Table 7) revealed that Positive Gain was significantly related to parent Self-efficacy (r = .51, p < .001) but none of the other predictors.

A two-step hierarchical regression was conducted with Positive Gain as the dependent variable and predictors entered in an *a priori* order (Table 8). Stressors were entered at Step 1 and Resources and Supports were entered at Step 2.

Table 8

Summary of Hierarchical Regression Analysis for Variables Predicting Positive Gain

Variable	B	95% CI for B		SE B	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.044	.044
Child Health	0.07	-0.05	0.19	0.06	0.17	0.021		
Adaptive Skills	0.00	0.00	0.00	0.00	0.02	0.000		
Maladaptive Behaviour	0.00	-0.01	0.01	0.01	-0.02	0.000		
Stigma	0.05	-0.06	0.15	0.05	0.12	0.012		
Financial Need	0.00	-0.01	0.02	0.01	0.07	0.004		
Step 2							.407	.364**
Child Health	0.00	-0.11	0.11	0.05	0.00	0.000		
Adaptive Skills	0.00	0.00	0.00	0.00	0.13	0.011		
Maladaptive Behaviour	0.00	-0.01	0.01	0.01	0.00	0.000		
Stigma	0.08	-0.02	0.17	0.05	0.20	0.029		
Financial Need	0.02	0.00	0.03	0.01	0.26	0.052**		
Support	0.02	-0.02	0.05	0.02	0.10	0.009		
Self-efficacy	0.60	0.38	0.82	0.11	0.68	0.335**		
Active Coping	-0.01	-0.25	0.23	0.12	-0.01	0.000		
Support Coping	-0.06	-0.28	0.16	0.11	-0.06	0.003		
Negative Coping	-0.06	-0.25	0.14	0.10	-0.07	0.004		

Note. *p < .05, **p < .01

The hierarchical multiple regression revealed that, at Step 1, stressors did not significantly contribute to the regression model, F(5,58) = 0.53, *p* = .753: accounting for only 4.4% of the variation in Positive Gain. Adding the parents' resources and supports to the regression model at Step 2 explained an additional 36.4% of the variation in Positive Gain and this change in R^2 was significant, F(5,53) = 6.51, *p* < .001. The final model accounted for 40.7% of the variance in Positive Gain, with significant coefficients for Financial Need (*p* = .001) and Self-efficacy (*p* < .001). Surprisingly, individuals with *greater* Financial Need were more likely to endorse positive outcomes related to having a child with DD. Parents with higher Self-efficacy ratings were more likely to report positive outcomes related to having a child with DD.

Predictors of Quality of Life

Correlations comparing the strength of the relationships between Quality of Life and potential predictors (Table 7) revealed that Quality of Life was significantly related to a number of variables, including Financial Need (*r* = -.53, *p* < .001), Child Health (*r* = .42, *p* < .001), Adaptive Skills (*r* = .32, *p* = .005), Stigma (*r* = -.24, *p* = .038), Support (*r* = .39, *p* = .001), Self-efficacy (*r* = .39, *p* = .001), and Negative Coping (*r* = -.42, *p* < .001).

A second two-step hierarchical regression was conducted; this time with quality of life as the dependent variable (Table 9). As in the previous regression, stressors were entered at Step 1 and resources and supports were entered at Step 2.

The second hierarchical multiple regression revealed that, at Step 1, stressors contributed significantly to the regression model, F(5,57) = 5.505, *p* < .001, and accounted for 32.6% of the variance in parents' Quality of Life ratings. Step 1 of the model revealed significant coefficients for Financial Need (*p* < .001) and Child Health (*p* = .017). Adding the parents' resources and supports to the regression model at Step 2 explained an additional 18.6% of the variation in quality of life and this change in R^2 was significant, F(5,52) = 3.95, *p* = .004. The final model accounted for 51.1% of the variance in Quality of Life ratings, with significant coefficients for Financial Need (*p* = .004), Support (*p* = .002), Self-efficacy (*p* = .010), and Negative Coping (*p* = .030). As expected, parents who reported less Financial Need, less frequent use of Negative Coping styles (i.e., denial, behavioural disengagement, self blame), a greater number of sources of Support, and greater Self-efficacy also reported higher Quality of Life ratings.

Table 9

Summary of Hierarchical Regression Analysis for Variables Predicting Quality of Life

Variable	B	95% CI for B		SE B	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.326	.326**
Child Health	7.63	1.42	13.83	3.10	0.32	0.072*		
Adaptive Skills	0.01	-0.18	0.20	0.09	0.01	0.000		
Maladaptive Behaviour	-0.26	-0.87	0.36	0.31	-0.09	0.008		
Stigma	0.43	-5.11	5.96	2.76	0.02	0.000		
Financial Need	-1.75	-2.67	-0.83	0.46	-0.45	0.172**		
Step 2							.511	.186**
Child Health	4.74	-1.23	10.71	2.98	0.20	0.024		
Adaptive Skills	-0.02	-0.19	0.16	0.09	-0.03	0.000		
Maladaptive Behaviour	-0.15	-0.76	0.47	0.31	-0.05	0.002		
Stigma	2.36	-3.01	7.72	2.67	0.10	0.007		
Financial Need	-1.34	-2.23	-0.45	0.44	-0.34	0.086**		
Support	3.31	1.32	5.30	0.99	0.34	0.105**		
Self-efficacy	16.45	4.18	28.71	6.11	0.31	0.068*		
Active Coping	-2.59	-16.10	10.92	6.73	-0.05	0.001		
Support Coping	0.97	-11.17	13.11	6.05	0.02	0.000		
Negative Coping	-11.88	-22.59	-1.17	5.34	-0.26	0.047*		

Note. **p* < .05, ***p* < .01

Predictors of Mental Health Difficulties

Correlations comparing the strength of the relationships between Mental Health Difficulties and potential predictors (Table 7) revealed that Mental Health was significantly related to a number of variables, including Financial Need (*r* = .51, *p* < .001), Child Health (*r* = -.39, *p* = .001), Adaptive Skills (*r* = -.43, *p* < .001), Stigma (*r* = .46, *p* < .001), Self-efficacy (*r* = -.34, *p* = .004), and Negative Coping (*r* = .55, *p* < .001).

A third and final two-step hierarchical regression was conducted with Mental Health as the dependent variable (Table 10). The predictors were the same as those in the first two regressions and entered in the same order.

Table 10

Summary of Hierarchical Regression Analysis for Variables Predicting Mental Health Difficulties

Variable	B	95% CI for B		SE B	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.426	.426**
Child Health	-0.12	-0.30	0.05	0.09	-0.17	0.019		
Adaptive Skills	0.00	-0.01	0.00	0.00	-0.16	0.017		
Maladaptive Behaviour	0.01	-0.01	0.03	0.01	0.11	0.011		
Stigma	0.21	0.05	0.37	0.08	0.29	0.071**		
Financial Need	0.04	0.02	0.07	0.01	0.36	0.112**		
Step 2							.562	.136*
Child Health	-0.05	-0.22	0.13	0.09	-0.06	0.002		
Adaptive Skills	0.00	-0.01	0.00	0.00	-0.17	0.019		
Maladaptive Behaviour	0.00	-0.01	0.02	0.01	0.03	0.001		
Stigma	0.12	-0.03	0.28	0.08	0.17	0.021		
Financial Need	0.03	0.01	0.06	0.01	0.28	0.059*		
Social Support	0.03	-0.02	0.09	0.03	0.11	0.012		
Self-efficacy	-0.26	-0.61	0.10	0.18	-0.16	0.018		
Active Coping	-0.04	-0.42	0.35	0.19	-0.02	0.000		
Support Coping	-0.24	-0.59	0.12	0.18	-0.13	0.015		
Negative Coping	0.52	0.21	0.83	0.15	0.36	0.095**		

Note. **p* < .05, ***p* < .01

This third hierarchical multiple regression revealed that, at Step 1, stressors contributed significantly to the regression model, F(5,58) = 8.619, $p < .001$, and accounted for 42.6% of the variation in parents' ratings of their child’s Mental Health Difficulties. Step 1 of the model revealed significant coefficients for Financial Need ($p = .001$) and Stigma ($p = .009$) but none of the child variables contributed significantly. Adding the parents’ resources and supports to the regression model at Step 2 explained an additional 13.6% of the variation in Mental Health Difficulties and this change in R^2 was significant, F(5,53) = 3.30, $p = .012$. The final model accounted for 56.2% of the variance in parent Mental Health ratings, with significant coefficients for Financial Need ($p = .010$) and Negative Coping ($p =$

.001). Greater Financial Need and higher reported use of Negative Coping were predictive of poorer Mental Health.

Discussion

The present study was intended to provide a detailed picture of the experiences of Zambian parents of children with DD and the factors contributing to a greater degree of positive gain, better quality of life, and fewer mental health problems in this population. As expected, parent experiences were variable and indicative of varied stressors, as well as interpersonal differences in resources and access to supports.

Not surprisingly, the regressions revealed that Financial Need was significantly related to all three outcome measures. This finding was consistent with the results of Study 1, that showed many parents describing the multi-faceted way in which poverty impacted their experience of raising a child with DD. In a country like Zambia, where income disparities are pronounced, it is not surprising that differences in financial need will have such a significant impact on the outcomes of parents. While it was expected that greater Financial Need would lead to poorer Quality of Life and a higher likelihood of experiencing Mental Health challenges, I also found that individuals with greater Financial Need actually had significantly higher Positive Gain ratings. It was unclear why this was the case. However, one possibility is that parents with less Financial Need and therefore higher social status experience greater anxiety related to the social threat that having a child with DD engenders. Parents of higher SES may experience greater stress in anticipation of – and as a result of – increases in social stigma associated with having a child with DD. For example, research suggests that individuals of higher social status demonstrate greater anxiety related to social threat or the potential of a change in their social status (e.g., Gruenewald et al., 2006; Scheepers & Ellemers, 2005). Another possibility is that parents with greater financial need may be more likely to perceive the child with DD as adding meaning to their lives or giving them purpose. Future studies should explore the relationship between Financial Need and Positive Gain in parents of children with DD in greater detail.

The results that Self-efficacy is significantly predictive of Positive Gain and Quality of Life speaks to the importance of empowering parents. Indeed, our results are consistent with research suggesting that parenting Self-efficacy, or how empowered or confident parents feel about their ability to manage problems related to their child, has the potential to mediate the effect of child-related stressors on parental outcomes (e.g., Hastings & Brown, 2002). Interventions designed to encourage parent involvement in their children's interventions and address the need for information related to the child are effective and promote increases in parent Self-efficacy (Sofronoff & Forbotko, 2002). As a result, one factor that was not captured in the regression but is likely related to parent outcomes is that of access to information. Many parents in Study 1 alluded to challenges with accessing information about their children's condition. Having greater information about how best to support one's child will likely lead to greater feelings of Self-efficacy in the parent. This finding also speaks to the potential that clinicians and other front-line workers have in improving the lives of parents of children with DD in Zambia. By promoting access to relevant information and including parents in the intervention when possible, such front-line staff may be able to inspire feelings of self-efficacy in parents.

Interestingly, of the three styles of coping entered into the model, negative coping was the only one that was significantly predictive of any outcomes. Researchers such as Carver (1989) present the argument that coping strategies are not intrinsically adaptive nor maladaptive but become adaptive or maladaptive depending on how they are used or depending on the sociocultural context of the environment in which they are being studied. Based on the results of Study 1, we labeled the coping factor that was composed of denial, self-blame, and behavioural disengagement "negative coping"; making the assumption that it was maladaptive in this population. As expected, more frequent use of these "negative coping" strategies consistently predicted poorer outcomes for parents in this study. This finding reinforces the emphasis that some counsellors or agencies supporting parents of children with DD in Zambia have placed on helping parents let go of self-blame and denial. For example, many parents in Study 1 talked about the positive impact of having counsellors or other staff tell them that their child's condition was not their fault and having them encourage the parent to accept the child's condition.

Surprisingly, even though many parents in Study 1 discussed the importance of acceptance, the Active Coping factor which included the acceptance subscale, was not significantly related to any of the outcomes. This may be because, as described in greater detail in Study 1, acceptance seemed to be a complex concept for many parents which could have both negative and positive implications. For, example, some parents may be spurred on to learn more about the child's condition and do the best that they can for the child, while other parents may become resigned and passive. As a result, acceptance may not always be “active”, despite its inclusion in the active coping factor following the factor analysis. Additional research may needed to tease apart the impact of the acceptance and the other active coping strategies on parent outcomes.

Religious coping was discussed in great detail in Study 1; however, Support Coping (which included the religion subscale of the Brief COPE) was also not significantly related to any of the outcomes. It is possible that religious coping needed to be examined in greater detail and independently from other coping styles. Krageloh and colleagues (2012) found that level of religiosity and spirituality was related to the way religious coping was used relative to other coping strategies. Following a factor analysis, they found that the “turning to religion” item on the Brief COPE loaded with emotional support and instrumental support in the overall sample as it had in our study. However, when they divided their sample according to level of religiosity and spirituality, they found that the item did not load at all for individuals with higher levels of religiosity and spirituality, and loaded with maladaptive coping strategies (such as denial and behavioural disengagement) for individuals with lower levels of religiosity and spirituality. In highly religious countries such as Zambia, where the vast majority of respondents are likely to endorse engaging in some form of religious coping, it may be necessary to examine the manner in which participants engage with religion in greater detail.

Consistent with parent report in Study 1, Support was significantly predictive of more positive Quality Of Life outcomes for parents in the study. I was not able to tease apart which sources of support were most predictive of better outcomes (i.e., social/informal support versus formal support services); however, the results still speak to the importance of increasing access to support so that parents have a greater number of sources of support available to them. This will likely be most impactful for parents who have fewer informal supports available to them. In addition to highlighting the need for greater accessibility to formal supports, the results also highlight the importance of engaging families and friends in supporting parents of children with DD in order to increase the number of informal supports available to parents. Research by Mung'omba (2008) and Nyoni and Serpell (2012) also suggests that stigma related to disability may contribute to family rejection of the child with the disability. For example, Nyoni and Serpell (2012) interviewed parents of children with autism who reported that their family members suspected witchcraft or breach of cultural traditions as being the cause of the child's condition. Increasing public awareness and understanding about DD may therefore be one way to improve support outcomes for parents of children with DD.

In the present study, Child Health was significantly related to Quality of Life in Step 1 of the regression but was no longer significant once supports and resources were added to the model. This suggests that, although a children's health problems are a significant source of stress for many parents, the resources and supports available to a parent are a more significant predictor of their overall outcome than the stressor, and may serve to ameliorate the impact of the stressors. Similarly, although Stigma was significantly predictive of poor Mental Health at Step 1 of the regression, it was no longer significant once supports and resources were added to the model. Overall, the only stressor that was significantly predictive of any of the outcomes measured in a final model was Financial Need. This speaks to the power of supports and resources to impact parent outcomes above and beyond the challenges related to many stressors.

Despite the positive potential impact of the present study, there are some limitations. The use of cross-sectional data to make inferences about the impact of stressors on parent well-being may be limited. The same stressors may impact outcomes such as parent mental health differently at different points in the parent or child’s life. For example, although some child factors, such adaptive skills and maladaptive behaviour, did not significantly contribute to parent outcomes in the present study, the results may have been different if we had measured the impact of the child’s challenges over time. It is possible that the impact of child factors such as adaptive skills or maladaptive behaviour may be greater earlier in the child’s life, closer to the time the parent received the diagnosis, or as the child approaches adulthood.

There are also gendered differences in parents’ experiences as research from various countries, including sub-Saharan African countries like Zambia (e.g., Mwape et al., 2012; Tarkkonen, 2017), has established that parenting is a gendered experience. For parents of children with DD, there are likely aspects of the parenting experience that are more dominant for mothers versus fathers. For example, in a narrative review examining the experiences of immigrant fathers raising children with DD, Khanlou and colleagues (2015) found that social support programs specifically for fathers were rare and fathers reported feeling excluded or ignored during medical or therapy appointments for their child. In the present study, I specifically recruited primary caregivers of children with DD and, in African countries, women tend to shoulder the bulk of the caregiving role (Mckenzie et al., 2013). Therefore, it was not surprising that the majority of participants in this study were women. I did not have a large enough sample of men to do a meaningful comparison between men and women in order to explore potential differences. Future research should examine the experiences of Zambian fathers of children with DD, in particular, as well as any differences between female and male caregivers of children with DD. Such research could provide valuable direction for more targeted intervention for families.

Another issue to consider is that many parents in Study 1 discussed challenges related to marital discord, or the support they received from their husbands, as significantly impacting their experience of raising their child. However, no measures explored marital satisfaction, marital discord, or spousal support in great detail. Responses provided on the single item measures where parents rated their satisfaction with their spouses or the degree of support received from their spouses on Likert-type scales were significantly positively skewed, even though discussions with parents in Study 1 suggest that parents' marital experiences are far more variable. Therefore, it seems as though the marital experiences of parents in this study were not accurately captured by the measures selected for this purpose. Another limitation was that not all questionnaires in this study had been used in Zambian samples before and none of the questionnaires had been formally translated into local languages. This presented a challenge for participants who were not fluent in English. When questionnaire items were read to the participant verbatim and were not understood, I or a research assistant attempted to rephrase the questionnaire item or provide clarification (in English), or provided an on-the-spot translation of the item if the participant still did not understand the item in English. Two questionnaire administrators who understood the local language were typically present (typically me and a research assistant) and could verify translations provided by one another; however, this was not an official translation and the administrator's interpretation of the item or the translation provided may have skewed the responses. An ideal translation process should include steps to ensure that the validity and reliability of the questionnaire is still intact following translation (Danielson et al., 2015).

An additional limitation was that, due to the close living quarters of some families and limitations related to childcare and transportation, questionnaires were sometimes completed in the home with other people present, and with limited privacy at times. This may have resulted in parents feeling pressured to provide responses that they would not have provided if complete privacy were possible.

A final limitation was that although coping was a significant resource discussed in Study 1 it proved difficult to measure in the present study. The Brief COPE, that was used in the present study, has a variable factor structure across studies and the sample size of the present study was relatively limited for a factor analysis although one was conducted in the present study. Additionally, some types of coping, such as religious coping and acceptance, may have required more detailed analysis separate from the other coping strategies. In considering the importance of coping, based on the literature and based on the interviews I conducted in Study 1, I felt it was important to examine coping in greater detail. Specifically, I wondered whether exploring the interplay between coping and other factors that were not explicitly measured in this study (e.g., executive functioning) may help us better understand coping in Zambian parents of children with DD.

Study 3: The Relationship Between Coping and Executive Function in Zambian Parents of Children with Developmental Disabilities

It is well established that parents of children with Developmental Disabilities (DD) experience greater levels of stress than parents of typically developing children (e.g., Cantwell et al., 2014; Gallagher et al., 2010; Gupta, 2007). Living with the chronic stress resulting from the heightened demands of caring for a child with DD is associated with a number of negative physical health (e.g., Lovell & Wetherell, 2011), mental health (e.g., Bishop et al., 2007), and cognitive effects (e.g., Lovell et al., 2014). Specific cognitive effects include impairments in learning and memory (Romero-Martinez et al., 2020) and executive functions (Romero-Martinez et al., 2020).

The cognitive effects of chronic stress are often attributed to hyperactivity of the Hypothalamic-Pituitary-Adrenal (HPA) axis which involves the hypothalamus releasing corticotropin releasing hormone (CRH) and arginine vasopressin in response to a stressor. CRH and arginine vasopressin, in turn, trigger the secretion of adrenocorticotropic hormone from the pituitary gland, resulting in the release of glucocorticoids by the adrenal cortex. To modulate the response of the HPA axis, glucocorticoids regulate the release of additional CRH and arginine vasopressin by binding to corticosteroid receptors (Lupien et al., 2009).

Under normal circumstances, feedback loops are triggered at various levels of the HPA system once the stressor has subsided, allowing the system to return to homeostasis (Lupien et al., 2009). Under conditions of chronic stress, the HPA axis is hyperactive, resulting in excess levels of cortisol (hypercortisolemia; Allen et al., 2017; Correa et al., 2015). This hypercortisolemia has been found to have detrimental effects on both the structure and function of several neuroanatomical structures related to cognition (Conrad, 2008; Girotti et al., 2018), including corticolimbic structures and the prefrontal cortex (Girotti et al., 2018). Additionally, the extended exposure to high levels of glucocorticoids that results from chronic stress is neurotoxic, as glucocorticoids have the capacity to disrupt a number of neurotransmitter systems, synaptic plasticity, neurogenesis, and neuronal death, resulting in increased cognitive impairment (Correa et al., 2015). In individuals who are not chronically stressed, the activation of the stress system also results in the release of dehydroepiandrosterone, an antiglucocorticoid that reduces glucocorticoid levels, and promotes neuronal survival and repair (Correa et al., 2015). However, research suggests that informal caregivers (typically family members) of individuals with long-term support needs show reduced levels of dehydroepiandrosterone, resulting in increased susceptibility to negative cognitive outcomes (e.g., Correa et al., 2015; Jeckel et al., 2010).

Informal caregivers (e.g., parents and other family members) of individuals with long-term support needs, such as children with DD, not only demonstrate evidence of the detrimental impact of chronic stress (Romero-Martinez et al., 2020), but are susceptible to experiencing detrimental effects resulting from acute stress as well. Unlike the robust evidence demonstrating the negative impact of chronic stress on cognition (Correa et al., 2015), research on the cognitive impact of acute stress is mixed, suggesting that acute stress can have both a positive and negative impact (Girotti et al., 2018). The most prevalent theory reconciles these mixed results by speculating that acute stress biases cognition to process information that is more directly related to the current stressor by allocating finite resources to deal with the stressor at hand, to the detriment of other cognitive functions (Shields et al., 2016). In their summary of the literature on the cognitive impacts of acute stress, Girotti and colleagues (2018) state that the acute stress response enhances sensory gain and environmental scanning and activates saliency networks centred around the amygdala, cingulate cortex, hypothalamus, insula, striatum, and locus coerulus. Conversely, acute stress negatively impacts processes underlying working memory, problem solving, and cognitive flexibility. In their meta-analytic review, Shields and colleagues (2016) indicate that stress impairs cognitive function through more than one pathway, thus complicating the interpretation of the mixed evidence in the literature even further.

The differences in the cognitive effects of acute and chronic stress are supported by physiological evidence. For example, the ventral tegmental area dopamine circuitry (VTA-DA), another system activated by stress, demonstrates context-dependent and nuanced responses to acute stress, whereas chronic stress results in profound changes in the VTA-DA circuitry, that may result in degeneration and a loss of VTA-DA neurons over time (Douma & Kloet, 2019). This VTA-DA system is important for linking internal states with the appraisal of environmental stimuli, allowing an individual to form an appropriate behavioural response to the stressor (Douma & Kloet, 2019). Research by De Andres-Garcia and colleagues (2012) suggests that caregivers of individuals with autism spectrum disorders show increased impairment resulting from acute stress, when compared to parents of children without autism spectrum disorders. Taken together, this research suggests that, when compared to other parents, parents of children with DD are at risk for a number of health-related and cognitive challenges related to chronic stressors, such as ongoing financial challenges resulting from the child's increased healthcare needs and intensive caretaking over many years, and are also more likely to experience impairment resulting from acute stressors such as their child experiencing a temporary health or behavioural crisis when compared to other parents. The negative impact of chronic stress on the cognition of parents of children with DD, and the impact on executive functions specifically, results in these caregivers being compromised in their ability to respond to the increased demands related to caring for their children.

Executive Functions

Executive functions describe those cognitive processes that regulate behaviour and facilitate the attainment of chosen goals. Many definitions exist; however, these processes are typically understood to include abilities that control goal-oriented cognitive, behavioural, and emotional functioning; including skills such as working memory, planning, task initiation, and inhibition (Gioia et al., 2002). There remains debate about whether these skills are separate, yet related, constructs or whether they represent subdomains of a unitary construct (Gioia et al., 2002). Executive functions are often measured via performance measures that tap into individual skills falling under the umbrella of executive functions. By design, these measures assess individual executive function subdomains and do not allow for the possibility of measuring an overarching executive function construct. Therefore, performance measures tend to reinforce the conceptualization of executive functions as separate constructs (Gioia et al., 2002). Gioia and colleagues (2002) argue that such methods have additional shortcomings; including limited ecological validity and designs that often confound the executive function skill with some aspect of the test content (e.g., vocabulary skill with verbal fluency). By contrast, questionnaire measures such as the Behavior Rating Inventory of Executive Function (BRIEF; Gioia et al., 2000) allow for the derivation of scores that represent performance across facets of individual executive functioning skills, as well as possible higher order multidimensional constructs. Factor analysis of the BRIEF supports the idea that one or more overarching constructs subsume individual executive functioning skills (Gioia et al., 2002). As an additional benefit, questionnaire measures are more ecologically valid in their assessment of perceptions of broader everyday functioning (Gioia et al., 2002). Such information allows researchers and clinicians to approximate an individual's ability to apply their executive functioning skills within the context of the demands of their daily lives.

Girotti and colleagues (2018) argue that executive functioning skills are necessary for the execution of everyday adaptive behaviours, including an individual's ability to adapt to unforeseen events and generate solutions to challenges. Similarly, for parents, Kienhuis and colleagues (2010) describe executive functions as being an important component of a parent's ability to attend to their child's cues, plan behaviour, adapt and respond flexibly to the child, problem-solve and make appropriate decisions. Deater-Deckard et al. (2012) found that good maternal executive functioning was critical to minimizing harsh parenting in the context of challenging child behaviour, particularly in calm, predictable environments. In addition to promoting more positive parenting, Hofmann and colleagues

(2012) propose that intact executive functioning skills are necessary for an individual to be able to pursue self-regulatory goals and are therefore related to the implementation of coping strategies. It is not surprising, then, that research consistently provides evidence of a relationship between executive function and coping (e.g., Grech et al., 2017; Rodriguez Villegas & Salvador Cruz, 2015).

Coping

According to Lazarus and Folkman's (1987) classic transactional theory of stress and coping, coping is defined as the thoughts and behaviours that individuals use to manage stressors. The theory suggests that coping is employed in an effort to restore equilibrium (Lazarus & Folkman, 1987). The manner in which specific coping strategies are categorized differs across studies and depending on what measurement tools are utilized. For example, Lazarus and Folkman (1987) group coping strategies into two broad categories: problem-focused strategies and emotion-focused strategies. Generally, problem-focused strategies involve the pursuit of goals related to altering the stressful situation with the goal of solving the problem and preventing the stressful situation from recurring in the future. By contrast, emotion-focused strategies are rooted in the present and involve processes aimed at reducing negative emotions resulting from the stressor without addressing the environment or potential for the stressful situation to reoccur (Folkman & Lazarus, 1984). However, Carver et al. (1984) suggest that the distinction between problem-focused and emotion-focused coping, though important, is overly simplistic; providing factor analytic evidence that coping, as measured by questionnaire measures, tends to form more than two factors. Their 60-item measure of dispositional coping, the Coping Orientations to Problems Experiences (COPE), was developed to measure 14 discrete coping behaviours; however, factor analysis did not confirm this 14-factor structure in the original sample (Carver et al., 1989) and as the measure has been used in subsequent studies, both the number of factors, and the items that load together, has differed (Tang et al., 2016).

Executive Functions and Coping

Despite variability in how both executive functions and coping strategies are measured and categorized, a number of studies have provided evidence that executive functions are predictive of coping strategy use. Results highlight both the positive relationships between strong or intact executive function and the use of adaptive or active coping strategies as well as the manner in which impairment in executive function impacts the coping strategies that people use. For example, Krpan and colleagues (2007) found that, in participants with traumatic brain injury, better executive performance was related to increased use of problem-focused coping. Conversely, lower performance on executive function tasks was related to increased use of emotion-focused coping. In research with patients with multiple sclerosis, Grech and colleagues (2017) found that better performance on a *specific* executive function subscale (verbal fluency) predicted higher use of acceptance, restraint, social support, religion, and total coping, while poorer *overall* performance on the total executive function index predicted greater use of behavioural disengagement, denial, religion, and total coping. Both research teams theorized that people with impaired executive functioning may turn to maladaptive coping strategies or rely on coping strategies that are less cognitively demanding (Grech et al., 2017; Krpan et al., 2007).

Research suggests that the types of coping strategies that people use can have varying effectiveness at alleviating stress and a number of studies have explored this with parents of children with DD specifically. For example, research with parents of children with DD, including intellectual disabilities and autism spectrum disorder, suggests that problem-focused coping tends to be more effective than emotion-focused coping (e.g., Essex et al., 1999; Miller et al., 1992; Smith et al., 2008). In a study of Finnish families, Taanila and colleagues (2002) found that families who had better outcomes tended to have multiple coping strategies. Several studies also suggest that coping strategies act as mediators or moderators between stressors and outcomes for caregivers and families of children with DD. For example, Dardas and Ahmad (2013) found that seeking social support and escape avoidance were moderators in the relationship between stress and quality of life among parents of children with autism spectrum disorder residing in Jordan. Peer and Hillman (2012) found that, while increased social support resulted in lower perceptions of stress among American parents of individuals with intellectual disabilities, when coping style was factored in, the relationship between social support and stress was no longer significant but still notable (partial mediation). Peer and Hillman (2012) hypothesize that parents' coping styles impact the amount of stress they experience resulting from the nature and stability (or lack thereof) of their social support systems.

Taken together the research suggests that, through multiple neurological pathways, chronic stress negatively impacts executive function for parents of children with DD, and results in increased susceptibility to the negative impacts of acute stress as well (e.g., Correa et al., 2015; De Andres-Garcia et al., 2012; Shields et al., 2016). Since executive functions are cognitive abilities that regulate behaviour and underlie the execution of adaptive behaviours to facilitate goal attainment (Girotti et al., 2018), this provides a theoretical rationale for why there would be a relationship between executive function and coping behaviour. This relationship is supported by research providing links between executive function skills and the coping strategies individuals tend to use (e.g., Grech et al., 2017; Krpan et al., 2007). Evidence suggesting that the use of specific coping strategies can significantly impact parent outcomes (e.g., Essex et al., 1999; Miller et al., 1992; Smith et al., 2008) highlights the need to consider executive function and coping when exploring relationships between stressors and outcomes. Little research has touched on any of these issues in a Zambian population.

Executive Function and Coping in Zambia

While some research exists examining executive functions and coping strategies in parents of children with DD from other cultures, these variables may be particularly susceptible to cultural differences, as culture influences what individuals pay attention to and how much they value particular ideas and approaches (Kelkar, Hough, & Fang, 2013). It is likely that some executive functioning skills and some coping strategies have more utility, and are therefore more likely to be well-developed, in certain cultural contexts. Indeed, research has found differences from North American standards in executive functioning test norms in Zambian populations (Hestad et al., 2016) and in the factor structure of Carver's (1997) brief version of the COPE in a Kenyan sample (Kimemia et al., 2011). It is important to note, however, that such differences may be, at least partially, an artefact resulting from the use of Western measures that have not been adapted or normed for the Zambian population. Similar to results from Western countries, Hestad and colleagues (2016) found that education and English literacy were significantly predictive of performance on many neuropsychological tests among Zambian adults, even after controlling for a number of other variables. Nell (2012) reports that neuropsychological testing norms developed in the United States and other Western countries have typically been based primarily upon participants who are relatively homogeneous in regard to socioeconomic status (middle class), ethnicity (European ancestry), and education (average high school with some college). The homogeneity of the normative group results in difficulties when interpreting data collected from participants that differ from the normative group. Further, normative demographic corrections often do not generalize well because of population differences in effects of aging, as well as education, gender and ethnicity in various international (especially non-Western) settings. Consequently, background differences including education and English literacy can have major effects on neuropsychological test results when the tests are used in countries where people have different linguistic, cultural and educational experiences than the U.S. standardization sample (Nell, 2012).

Existing research on executive functioning and coping in Zambian samples is sparse and, although research exists on the executive functioning of Zambian adults (e.g., Hestad et al., 2016; Kabuba et al., 2016), no studies have examined the relationship between executive functioning and coping in a Zambian sample. Additionally, although a qualitative study by Nyoni and Serpell (2012) found that Zambian parents of children with autism reported the use of various coping strategies such as empowerment, humor, openness, faith and belief in God's healing power, no quantitative research was found on coping strategy use among Zambian parents of children with DD.

The present study provides an exploration of the relationship between executive functioning and coping in Zambian parents of children with DD. I chose to focus on the relationship between executive functions and coping, specifically, rather than exploring the relationship between executive functions and parent outcomes more broadly. As outlined above, there is both theoretical rationale and research evidence that support the likelihood of such a relationship. There is less reason to expect a significant relationship between executive functions and other variables, such as the parent outcome measures explored in Study 2 (Positive Gain, Quality of Life, Mental Health Problems). I hope that a better understanding of the relationship between executive functions and coping can be used to more precisely inform intervention in order to potentially reduce the negative impact of chronic stress on Zambian parents of children with DD. Due to research by Hestad and colleagues indicating that education and English literacy were significantly predictive of neuropsychological test performance among Zambian adults, and as educational attainment among Zambians is assumed to be related to socioeconomic status, these factors were explored in the analysis as well. Specifically, I explored (1) differences in executive functioning or coping scores depending on whether parents endorsed being fluent in English or not, (2) whether (and how strongly) executive functions and coping strategies are correlated, (3) differences in coping strategy use between individuals with clinical-level deficits in executive functioning skills compared to individuals with average executive functioning skills, and (4) whether specific executive functioning skills predict the use of specific types of coping strategies, after controlling for the potential impact of education level and financial need.

As I anecdotally observed in Study 2 that many participants who reported that they were not fluent in English were able to easily converse in English, I hypothesized that (1) there would be no significant differences in executive functioning or coping scores between participants who endorsed English fluency and those who did not. I also hypothesized that (2) executive functioning skills and coping strategies would be significantly correlated with one another and that (3) individuals with clinical level deficits in executive functioning would be significantly less likely to engage in the use of active coping strategies. Finally, I hypothesized that (4) some specific executive functioning skills would be predictive of the use of specific coping strategies.

Methods

A researcher-administered questionnaire, consisting of measures used to assess parent stressors, outcomes, executive functioning skills, and coping strategies, was completed with parents of children with DD residing in Lusaka (Appendix F). In order to have a representative sample, not all participants were fluent in English. For participants who were not fluent in English I or a research assistant translated items into one of the two major local languages (iciBemba or iciNyanja).

Participants

Participants were a subsample of 44 Zambian primary caregivers of children with DD who had previously participated in Studies 1 and 2. The caregivers ranged in age from 22 to 72 years of age (M = 39.16, SD = 11.36) and the children with DD whom they cared for (51.2% males) ranged in age from 3 to 19 years of age (M = 10.82, SD = 4.05).

Table 1

Parent Education Levels

Highest Level of Education Reached	*n*	%
Less than 7th Grade	12	27.3
8th or 9th Grade	9	20.5
10th or 11th Grade	8	18.2

Secondary School Graduate	7	15.9
Partial College/University	1	2.3
College/University Graduate	6	13.6
Graduate Degree	1	2.3

All participants were women who were either the child's biological mother (*n* = 39; 88.6%) or the child's grandmother (*n* = 5; 11.4%). More than half (63.6%, *n* = 28) of the participants were married and 63.6% (*n* = 28) described themselves as being fluent in English; however, many parents who did not endorse being fluent in English were still able to converse in English. The majority (*n* = 31; 73.8%) of respondents did not have paid employment and education levels were varied, ranging from below 7th grade to graduate level education (see Table 1).

Procedure

Data collection for the present study was completed in December 2019. Informed written consent was obtained prior to data collection. All questionnaires were completed in person with a me or a research assistant who was able to provide clarification if any questionnaire items were unclear to the participant. The questionnaires were completed in a classroom at a local school.

Measures

Executive Function

Roth and colleagues' (2005) adult version of the BRIEF (BRIEF-A) was used to measure executive functioning in the participants. The BRIEF-A provides a measure of the respondent's perspective regarding their own executive functioning difficulties. The measure produces two summary index scales – the Behavioural Regulation Index (BRI) and the Metacognition Index (MI) - and a scale reflecting overall executive functioning (Global Executive Composite, GEC) based on theoretical and statistical considerations. The BRI is a composite of four subscales, measuring inhibition, shifting, emotional control, and self-monitoring. The MI is a composite of five subscales, measuring initiation, working memory, planning/organization, task-monitoring, and organization of materials. The measure demonstrates moderate to high internal consistency for the clinical scales (α = .73 to .90), and high internal consistency for the indices BRI, MI, and GEC (α = .93 to .96; Roth et al., 2005). Scores across the subscales and indices are converted into standardized ratings (*T* scores) with higher scores reflecting greater difficulty, or poorer executive function, in that domain. Clinical levels of impairment in executive functioning skills are defined as *T* scores of 65 or greater (Roth et al., 2005). The original version of the measure (BRIEF) has been used with participants from various countries, including African countries like South Africa (Dollman et al., 2017) and Uganda (Familiar et al., 2015). No studies were found specifically examining validity of the BRIEF-A in an African sample; however, a validation study of the original measure (BRIEF) in a Ugandan sample found that a factor analysis resulted in two main factors comprising the BRI and MI scales (Familiar et al., 2015), similar to results in North American samples (Roth et al., 2015).

To address the risk of respondent bias, the BRIEF-A includes three validity scales: negativity, infrequency, and inconsistency (Roth et al., 2005). The negativity scale measures the extent to which the respondent answered selected BRIEF-A items in an unusually negative manner. The infrequency scale indicates the degree to which the respondent endorsed items in an atypical fashion relative to the normative sample. The inconsistency scale indicates the extent to which sets of two similar BRIEF-A items, which tend to receive similar ratings, were rated in an inconsistent manner by the respondent (Roth et al., 2005). All participants included in the analyses received “acceptable” ratings across all three validity scales.

Coping

Carver's (1997) brief situational format of the COPE inventory (Carver et al., 1989) was used to measure parents' coping strategies. Reliability for the measure is acceptable with most subtests demonstrating internal consistency of α between .62 and .92 (one subtest demonstrated internal consistency of α = .45). As discussed earlier, the measure demonstrates variable factor structure across studies (Tang et al., 2016). As the participants in this study were comprised of a subsample of participants from Study 2, analysis of the brief COPE in the present study was based on the results of the factor analysis conducted on the broader parent sample. Specifically, item ratings were combined to form three factors that were used to provide summary ratings and the items included in each factor were consistent with the factors established in Study 2. 1. The Active Coping factor included the Active Coping, Planning, and the Acceptance subscales; however, item 20 ("I've been accepting the reality of the fact that it has happened") was excluded (as it had been in Study 2). 2. The Support Coping factor included the Emotional Support, Instrumental Support, and Religion subscales. 3. The Negative Coping factor included the Denial, Behavioural Disengagement, and Self Blame subscales. The remaining items from the brief COPE were excluded from further analysis as was done in Study 2. The final scores for each factor were calculated using the mean of the item scores included in that factor. These factors demonstrated strong internal consistency in the present sample, with the Active Coping factor demonstrating an internal consistency rating α = .81, the Support Coping factor α = .81, and the Negative Coping factor α = .82.

Financial Need

As in Study 2, Financial Need was measured using items from the questionnaire used in Wave 4 (2002) of the United Kingdom's Department for Work and Pensions' Families and Children Study (Phillips et al., 2003). Items required participants to rate a number of items in terms of whether they have access to the item, would like but cannot afford the item, or have no interest in the item. Items are extracted from several categories related to family well-being and social capital; including food/nutrition (7 items), clothing (7 items), durable goods (14 items), and social activities (6 items). Similar to the approach taken by Emerson and Hatton (2007), financial hardship was estimated by calculating the number of items that each family would like but cannot afford. Financial Need was approximately normally distributed in this sample with the number of items participants reported wanting but not being able to afford ranging from 3 to 34. Higher scores reflected greater Financial Need.

Results

Executive Functioning

On the BRIEF-A, the GEC summary *T* scores ranged from 37 to 87, with 36.4% of the sample falling above the clinical cut-off of 65. The percentage of participants falling above the clinical cut-off on individual subscales ranged from 6.8% (*n* = 3; self-monitoring) to 47.7% (*n* = 21; shifting).

Table 2

Executive Functioning Scores

BRIEF-A Domain				Above Clinical Cut-off	
	M	SD	Range	*n*	%
Global Executive Composite (GEC)	60.20	9.68	37-87	16	36.4
Inhibition	56.77	9.55	37-71	12	27.3
Shifting	60.80	8.41	43-78	21	47.7
Emotional Regulation	60.80	10.06	39-92	11	25
Self-Monitoring	57.59	8.45	37-70	3	6.8
Initiation	55.64	10.38	38-79	7	15.9
Working Memory	59.86	10.77	40-93	18	40.9
Planning	58.70	9.15	39-83	18	40.9
Task-Monitoring	56.84	9.43	37-69	14	31.8
Organization of Materials	53.57	7.96	37-75	4	9.1

Note. N = 44

Coping

Scores on the Support Coping factor ranged from 1.83 to 4.00 (*M* = 3.06, *SD* = 0.64), scores on the Negative Coping factor ranged from 1.00 to 3.50 (*M* = 1.82, *SD* = 0.71), and scores on the Active Coping factor ranged from 1.20 to 4.00 (*M* = 3.09, *SD* = 0.64).

Role of English Fluency

In order to ensure that participants' comfort with the English language did not significantly affect ratings on any of the variables, participants who endorsed being fluent in English were compared to those who did not. First, the Educational Attainment variable was recoded into two levels, depending on whether participants were high school graduates or not and a chi-square test was conducted. The relationship between English Fluency and Educational Attainment was significant, X^2 (1, N = 44) = 13.01, p < .001. All participants who were high school graduates (n = 15) endorsed being fluent in English, compared to 45% (n = 13) of participants who were not high school graduates (n = 29). Next, *t* tests were conducted to examine mean differences in the remaining variables (see Table 4). Participants who endorsed being fluent in English reported having fewer Financial Needs on average than those who did not endorse English-language fluency. This difference approached significance but had a large effect size, (d = 0.60). Differences between the two groups in mean scores on the coping and executive functioning variables were not significant; however, differences in Task Monitoring (d = 0.62) and Organization of Materials (d = 0.60) approached significance, with large effect sizes.

Table 3

Differences in Variables Based on English Language Fluency

Variable	Fluent (*n* = 28)		Not Fluent (*n* = 16)		*t*	*p*
	M	*SD*	*M*	*SD*		
Support Coping	3.18	0.60	2.92	0.63	1.37	.178
Negative Coping	1.77	0.74	1.94	0.69	-0.77	.447
Active Coping	3.16	0.55	3.01	0.79	0.70	.487
BRIEF-A GEC	58.39	8.59	63.38	10.91	-1.68	.101
Inhibition	55.57	10.10	58.88	8.41	-1.11	.275
Shifting	59.57	7.79	62.94	9.26	-1.29	.205
Emotional Regulation	59.39	10.21	63.25	9.61	-1.23	.225
Self-Monitoring	57.04	8.46	58.56	8.63	-0.57	.570
Initiation	54.18	9.15	58.19	12.14	-1.24	.222
Working Memory	58.11	9.41	62.94	12.54	-1.45	.154
Planning	57.07	8.27	61.56	10.15	-1.60	.118
Task-Monitoring	54.82	9.44	60.38	8.56	-1.94	.059
Organization of Materials	51.82	6.74	56.63	9.17	-1.99	.053
Financial Need	17.93	6.46	21.69	6.02	-1.90	.064

Poor vs. Good Executive Functioning Groups

In order to explore the relationship between executive functioning and coping further, participants were then categorized into poor and good executive functioning groups according to the clinical cut-off proposed by the authors of the measure (Roth et al., 2005). Specifically, participants with a *T* score of 65 or greater on the BRIEF-A GEC were classified as having poor executive functioning skills as this corresponds with the clinically impaired range of the measure. Conversely, participants with a score of 64 or less were classified as having good executive functioning as these scores fell within the normal range.

The coping strategies of the good (*n* = 28) and poor (*n* = 16) executive functioning groups were compared using *t* tests. The two executive functioning subgroups significantly differed in their use of Negative Coping, *t*(40) = -2.95, *p* = <.001, *d* = .97, and Active Coping, *t*(39) = 2.79, *p* = .008, *d* = .89. Specifically, individuals with good executive functioning skills reported significantly less frequent use of Negative Coping (*M* = 1.60, *SD* = 0.68) than those in the poor executive functioning group (*M* = 2.23, *SD* = 0.62) and more frequent use of Active Coping (*M* = 3.31, *SD* = .57) than those in the poor executive functioning group (*M* = 2.77, *SD* = 0.62). Differences in participants' use Support Coping by executive functioning group were not significant *t*(42) = -1.19, *p* = .239, *d* = 0.38.

Correlations

Correlations were used to evaluate the degree to which coping and executive functioning are related (see Table 3). In addition to the GEC, the nine individual subscales of the BRIEF-A were also included in the correlations, in order to provide a nuanced view of which specific executive functions were related to specific Support, Negative, and Active Coping strategies, respectively. Parents' Educational Attainment and Financial Need were also included as variables in the correlation analyses, due to research indicating their potential impact on neuropsychological performance (Hestad et al., 2016), as previously described.

Correlations revealed a moderate and significant relationship between Support Coping and Active Coping. The relationship between Support Coping and Active Coping was positive, such that participants who endorsed using support-seeking coping strategies also endorsed using active coping strategies. Support Coping was not significantly related to any scores from the BRIEF-A.

Negative Coping was significantly related to the BRIEF-A GEC and to the Inhibition, Shifting, Self-Monitoring, Initiation, Planning and Organization, and Task-Monitoring subscales. All relationships were moderate in magnitude and positive, suggesting that individuals who reported greater difficulty across several domains of executive functioning were also more likely to endorse using Negative Coping.

Active Coping was significantly related to the BRIEF-A GEC, and to the Inhibition, Initiation, Working Memory, Planning, Task-Monitoring, and Organization of Materials subscales, with moderate to strong (Initiation and Planning) correlations. All relationships were negative, suggesting that individuals who reported better executive functioning were more likely to endorse using Active Coping.

As expected, Educational Attainment was significantly and strongly related to Financial Need, such that parents who attained higher levels of education reported less Financial Need. Parents' Educational Attainment was also significantly and negatively related to the BRIEF-A GEC, and to the Initiation, Working Memory, Planning and Organization, and Task-Monitoring subscales (*r* values ranging between -0.32 to -0.40). Educational Attainment was not, however, significantly related to Support Coping, Negative Coping, or Active Coping scores.

Table 4

Correlations Among Variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1.Support Coping	-													
2.Negative Coping	.04	-												
3.Active Coping	.38*	-.30	-											
4.BRIEF-A GEC	-.16	.36*	-.42**	-										
5.Inhibition	-.25	.43**	-.38*	.87**	-									
6.Shifting	-.12	.45**	-.30	.83**	.81**	-								
7.Emotional Reg	-.13	.14	-.12	.72**	.61**	.57**	-							
8.Self-Monitoring	.14	.33*	-.06	.63**	.65**	.52**	.40**	-						
9.Inititation	-.15	.46**	-.56**	.80**	.68**	.70**	.32*	.46**	-					
10.Working Memory	-.11	.30	-.33*	.93**	.76**	.70**	.62**	.59**	.72**	-				
11.Planning/ Organization	-.09	.36*	-.53**	.86**	.67**	.61**	.42**	.47**	.79**	.82**	-			
12.Task-Monitoring	-.17	.41**	-.47**	.85**	.72**	.66**	.50**	.60**	.71**	.83**	.77**	-		
13.Organization of Materials	-.24	.15	-.34*	.84**	.70**	.68**	.67**	.45**	.57**	.78**	.66**	.62**	-	
14. Educational Attainment	-.05	-.25	.05	-.32*	-.23	-.24	-.15	-.25	-.33*	-.33*	-.34*	-.40**	-.18	-
15.Financial Need	-.16	.34*	.08	.23	.31*	.25	.05	.23	.28	.22	.13	.25	.08	-.54**

Note. *p < .05, **p < .01

Financial Need was significantly related to Negative Coping, such that individuals endorsing higher levels of Financial Need also endorsed using Negative Coping strategies more frequently. Financial Need was not significantly related to either Support Coping or Active Coping. Financial Need was also significantly related to Inhibition on the BRIEF-A, such that individuals with greater Financial Need endorsed greater difficulty with inhibition skills but was not significantly related to any other executive functioning domains on the BRIEF-A.

Regressions

Finally, three two-step hierarchical regressions were conducted to analyze which executive functions were predictive of Support Coping, Negative Coping, and Active Coping, respectively. Individual subscale scores from the BRIEF-A were used as predictors, in order to provide a more specific level of insight into the relationship between executive functions and coping. Financial Need and Educational Attainment were entered at Step 1 one to control for their potential effects on coping.

The first regression, predicting Support Coping, revealed that, at Step 1, Financial Need and Educational Attainment did not significantly contribute to the regression model, F(2,41) = 1.20, *p* = .311: accounting for 5.5% of the variance in Support Coping. Adding executive functions to the regression model at Step 2 explained an additional 30.1% of the variance in Support Coping but this change in R^2 was not significant, *F*(9,32) = 1.66, *p* = .139. The final model accounted for 35.7% of the variance in Support Coping. Only Self-Monitoring significantly contributed to the final model (*p* = .011), accounting for 14.6% of the variance in Support Coping. Participants with poorer self-monitoring skills were more likely to endorse use of support-seeking strategies in order to cope. See Table 5.

Table 5

Summary of Regression Analysis for Executive Functioning Variables Predicting Support Coping

Variable	B	95% CI for B		SE(B)	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.055	.055
Financial Need	-0.03	-0.06	0.02	0.02	-0.27	.053		
Educational Attainment	-0.07	-0.20	0.07	0.06	-0.20	.028		
Step 2							.357	.301
Financial Need	-0.02	-0.06	0.02	0.02	-0.21	.025		
Educational Attainment	-0.06	-0.20	0.07	0.06	-0.18	.019		
Inhibition	-0.04	-0.08	0.00	0.02	-0.64	.080		
Shifting	0.03	-0.01	0.07	0.02	0.38	.038		
Emotional Regulation	0.00	-0.03	0.03	0.01	0.04	.001		
Self-Monitoring	0.04*	0.01	0.07	0.01	0.53	.146		
Initiation	-0.01	-0.04	0.03	0.02	-0.11	.003		
Working Memory	0.02	-0.02	0.06	0.02	0.34	.018		
Planning/Organization	0.02	-0.03	0.06	0.02	0.22	.010		
Task-Monitoring	-0.03	-0.07	0.01	0.02	-0.45	.048		
Organization of Materials	-0.03	-0.07	0.01	0.02	-0.40	.048		

Note. *$p < .05$, **$p < .01$

The second regression, predicting Negative Coping, revealed that, at Step 1, Financial Need and Educational Attainment did not significantly contribute to the regression model, F(2,39) = 2.65, *p* = .083, but accounted for 12% of the variance in Negative Coping. Adding executive functions to the regression model at Step 2 explained an additional 25.2% of the variance in Negative Coping but this change in R^2 was not statistically significant, *F*(9,30) = 1.34, *p* = .261. The final model accounted for 37.1% of the variance in Negative Coping, as shown in Table 6.

Table 6

Summary of Regression Analysis for Executive Functioning Variables Predicting Negative Coping

Variable	B	95% CI for B		SE (B)	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.120	.120
Financial Need	0.03	-0.01	0.07	0.02	0.28	.057		
Educational Attainment	-0.04	-0.18	0.10	0.07	-0.10	.007		
Step 2							.371	.252
Financial Need	0.02	-0.02	0.06	0.02	0.17	.016		
Educational Attainment	0.00	-0.15	0.15	0.08	0.00	<.001		
Inhibition	0.01	-0.04	0.06	0.03	0.10	.002		
Shifting	0.03	-0.02	0.08	0.02	0.34	.028		
Emotional Regulation	0.00	-0.03	0.03	0.02	0.03	<.001		
Self-Monitoring	0.01	-0.03	0.04	0.02	0.07	.002		
Initiation	0.01	-0.03	0.05	0.02	0.19	.010		
Working Memory	-0.02	-0.07	0.04	0.03	-0.23	.008		
Planning/Organization	0.01	-0.04	0.07	0.03	0.18	.007		
Task-Monitoring	0.01	-0.03	0.06	0.02	0.18	.008		
Organization of Materials	-0.03	-0.08	0.02	0.03	-0.38	.040		

The third regression, predicting Active Coping revealed that, at Step 1, Financial Need and Educational Attainment did not significantly contribute to the regression model, F(2,38) = 0.73, *p* = .730: accounting for only 1.6% of the variance in Active Coping. Adding executive functions to the regression model at Step 2 explained an additional 55.6% of the variance in Active Coping and this change in R^2 was significant, *F*(9,29) = 4.20, *p* = .001. The final model accounted for 57.3% of the variance, with significant coefficients for Self Monitoring (*p* = .040) and Initiation (*p* = .046) which uniquely accounted for 6.8% and 6.4% of the variance in Active Coping, respectively. Parents with poorer self monitoring and better initiation skills were more likely to endorse using Active Coping. See Table 7. Task-Monitoring accounted for 5.6% of the variance in Active Coping (*p* = .062) and Inhibition accounted for 4.5% of the variance in Active Coping (*p* = .093), although not statistically significant. Parents with better task-monitoring and better inhibition skills were somewhat more likely to endorse using Active Coping.

Table 7

Summary of Regression Analysis for Executive Functioning Variables Predicting Active Coping

Variable	B	95% CI for B		SE (B)	β	sr^2	R^2	ΔR^2
		LL	UL					
Step 1							.016	.016
Financial Need	0.01	0.46	-0.02	0.14	0.14	.014		
Educational Attainment	0.04	0.53	-0.09	0.12	0.12	.010		
Step 2							.573	.556**
Financial Need	0.02	0.16	-0.01	0.24	0.24	.031		
Educational Attainment	-0.01	0.88	-0.12	-0.02	-0.02	<.001		
Inhibition	-0.03	0.09	-0.07	-0.48	-0.48	.045		
Shifting	0.02	0.25	-0.02	0.28	0.28	.020		
Emotional Regulation	0.01	0.46	-0.02	0.15	0.15	.008		
Self-Monitoring	0.03*	0.04	0.00	0.38	0.38	.068		
Initiation	-0.03*	0.05	-0.06	-0.48	-0.48	.064		
Working Memory	0.03	0.15	-0.01	0.49	0.49	.032		
Planning/Organization	-0.01	0.52	-0.05	-0.18	-0.18	.006		
Task-Monitoring	-0.03	0.06	-0.07	-0.49	-0.49	.056		
Organization of Materials	-0.01	0.41	-0.05	-0.18	-0.18	.010		

Note. *$p < .05$, **$p < .01$

Discussion

Overall, the results of this study support existing literature on the strong relationship between executive functions and coping. Not surprisingly, executive functions accounted for the most variance in Active Coping, when compared to the two other coping styles. Active Coping was moderately strongly correlated to a number of executive functioning domains and participants with clinically significant levels of impairment in executive functioning were significantly less likely to engage in active coping strategies than individuals whose executive functioning skills fell within the average range. As suggested by Roth and colleagues (2012), active coping strategies, such as planning, may allow parents to better respond to stressors and improve outcomes. However, active coping strategies are also more cognitively demanding than more passive strategies and parents with significant impairments in executive function may be forced to rely on coping strategies that are less demanding (Grech et al., 2016). For parents of children with DD in Zambia, who likely face significant stressors and significantly greater barriers to accessing services and resources than many other research samples, being able to engage in active coping skills may be even more valuable.

The results of Study 1 and Study 2 highlight the importance of support in promoting positive outcomes for Zambian parents of children with DD; however, the relationship between executive functions and Support Coping seemed to be surprisingly weak. Specifically, Support Coping was not significantly correlated with any executive functioning variables and there were no significant differences in use of Support Coping between participants with good versus poor executive functioning skills. Finally, in the regression, the only variable that significantly contributed to the variance in Support Coping was Self-Monitoring. The result that parents with poorer self-monitoring skills were more likely to endorse use of Support Coping may be indicative of other factors, such as stigma, influencing the relationship between executive functions and Support Coping. For example, a recent review by Adugna and colleagues (2020) found that parents of children with disabilities in several sub-Saharan African countries, including Zambia, reported fear of being treated differently by others and the experience of stigma prevented them from seeking out treatment for their child’s condition. Additionally, cultural beliefs regarding the source of the disability (e.g., witchcraft) also prevented parents from seeking support (Adugna et al., 2020). Many items on the Self-Monitoring subscale of the BRIEF seem to reflect, in part, the respondent’s awareness of their impact on others and the consequences (social and otherwise) that their behaviour might have on others. Therefore, while many parents may be less likely to seek support due to the risk of stigma, parents with poorer Self-Monitoring skills may be more likely to express the need for support in order to address their immediate need, without thinking through the negative consequences this might have for them. They may also be less likely to learn from prior negative experiences related to support-seeking behaviour, due to a decreased ability to make connections between their behaviour and the outcome of that behaviour.

These results are notable as the research literature consistently outlines the relationship between social support and outcomes for parents of children with DD (e.g., Guralnick et al., 2008; Kyzar et al., 2012; Weiss, 2002). In Study 2 of the current project, I also found that parents who endorsed having a greater number of sources of social support reported having a higher quality of life. If other factors are influencing whether or not parents seek support, a positive course of action may be to engage communities and family members in offering support to parents of children with DD who may not seek it out independently. Educating Zambian communities on DD may serve to both reduce stigma, and also increase the likelihood that community members and extended family members will reach out to parents and offer support.

Interestingly, Negative Coping and one executive functioning subscale (Inhibition) were significantly correlated with Financial Need. Specifically, parents with greater Financial Need were more likely to engage in the use of negative coping strategies and tended to have more difficulty with inhibition. Additionally, although Negative Coping was significantly correlated with inhibition, after controlling for Financial Need and educational attainment in a hierarchical regression, neither Inhibition nor any other BRIEF-A subscale were significantly predictive of the variance in Negative Coping. One possibility is that parents with poorer executive functioning skills may be more likely to have greater financial need (e.g., poor management of finances due to poor planning skills) and may also be more likely to engage in negative coping strategies because their poor executive functioning skills make it more difficult for them to engage in more demanding coping strategies, such as active coping strategies. Another possibility is that parents with greater financial need are more likely to live in situations with greater environmental stress and adversity which may, in turn, have an impact on ratings of parental executive functioning (Monn et al., 2017).

Several studies have found a significant relationship between measures of socioeconomic status (e.g., household income, parent education, occupation) and executive functions, particularly in samples that are more heterogenous in socioeconomic status (Lawson et al., 2014). Interestingly, in a study examining maternal executive functioning in the context of homelessness, Monn and colleagues (2017) found that some aspects of executive functioning deteriorated under conditions of high stress or chaos, but others remained intact. There are a number of ways to measure socioeconomic status and other associated variables that may further confound the relationship between socioeconomic status and executive function. For example, St. John and Tarullo (2018) found that neighbourhood chaos moderates the relationship between socioeconomic status and executive functioning in children. Therefore, it is important to consider the ways that factors related to socioeconomic status that were not measured in this study, such as household or neighbourhood chaos, may also be impacting parents' executive functioning ratings. Parents with greater Financial Need, lower levels of education, housing insecurity, or living in unsafe neighbourhoods, may have an even greater number of stressors to contend with than their child's disability-related needs. As a result of this greater level of everyday strain, the conditions under which the parents regularly operate and through which they base their evaluations of their own executive functioning skills may be much further from the ideal than parents who have more stability (financial and otherwise). It is not surprising then, that Financial Need would not only impact executive functioning ratings, such as inhibition, but would also be positively related to parents engaging in more negative coping strategies such as behavioural disengagement and denial. Unfortunately, the results of Study 2 suggest that engaging in negative coping is related to poor outcomes for parents. It may be helpful for support staff to encourage parents to engage in more positive passive coping strategies (e.g., support-seeking or other emotion-focused strategies), when they are feeling too overwhelmed to engage in active coping strategies.

Given evidence of the value of coping and executive function in promoting better outcomes to parents facing significant stress, it is important to consider interventions that may be used to support parents in Zambia and more generally. Unfortunately, no research was found examining interventions for Zambian parents. Nevertheless, research on interventions in other populations are promising and future researchers may wish to establish the effectiveness of such interventions in this group. For example, a pilot study by Romero-Martinez and colleagues (2017) found that a cognitive behavioural therapy intervention focused on reducing health complaints and stress levels was effective at improving some cognitive functions, including selective attention, memory, cognitive flexibility, and planning, in caregivers of people with autism spectrum disorder. Several other studies have demonstrated the beneficial effects of cognitive behavioural interventions, including coping skills training, on promoting positive outcomes among related groups such as parents of children with DD in Western countries (e.g., Singer et al., 2007), parents facing economic hardship (e.g., Wadsworth et al., 2011), and parents with children undergoing medical procedures (e.g., Zelikovsky et al., 2001).

This study adds to the growing literature on the measurement of executive functioning in African populations. Unfortunately, however, there is still a need to establish culturally-valid measures of executive function in many cultural groups for which current measures have not been developed, adapted, or normed, including Zambia. Use of measures not validated in a particular sample can result in a number of issues including floor effects, ceiling effects, issues related to the comprehension of items, and the absence of culturally-relevant normative data for comparison (Robbins et al., 2013). While research by Adjorlolo (2016; 2018) suggests that tests of executive function commonly used in Western countries may maintain some ecological validity, diagnostic accuracy, sensitivity, and specificity when used in an African sample, other studies have found differences in executive function performance across cultures (e.g., Kelkar et al., 2013; Schmitt et al., 2019). Therefore, there remains a need to explore this issue further.

The decision to use the BRIEF-A, a well-established measure of executive functioning in Western countries, but one with limited research on its applicability in a Zambian sample, is considered to be both a limitation and a strength of the present study. The lack of normative data for this measure in a

Zambian sample is a limitation; however, this study now provides one of the first examinations of the measure in an adult Zambian sample. Future research should examine the utility of this measure in a larger sample. Another limitation of using executive functioning measures developed in the West, was the potential that participants in this sample may have interpreted some items differently than they were intended by the developers of the measure. The research team made efforts to clarify items with participants and provide culturally-relevant examples when needed; however, this reduced the standardization of the administration. The potential for biased interpretations due to language differences or differences in the colloquial understanding of certain words or phrases was briefly assessed by examining whether there were mean differences in any of the variables depending on whether participants described themselves as fluent in English or not. No differences in coping strategy use or executive functioning domains were statistically significant; however, differences in task-monitoring and organization of materials approached significance. Future research should examine comprehension of the BRIEF-A items in a Zambian sample in greater detail in order to more accurately speak to its utility as a measure of executive functioning for that population. It may be prudent to explore translation of the items into local languages and include culturally-relevant examples into the standardized measure.

Other limitations of the present study include the modest sample size which may have limited statistical power (e.g., some comparisons were not significant although the effect size was large), and the use of a self-report measure of executive function which may have introduced respondent bias into the sample. Having informant report data or laboratory measures of executive function to supplement these data would have enriched the study. Additionally, as discussed in Study 2, the use of cross-sectional data limits my ability to infer causality or to determine whether the relationships explored in this study may shift and change at different times in the lives of the parents and their children. Another limitation that was previously discussed in Study 1 and Study 2 is that all participants in this sample were all urban-dwelling parents; thus limiting our ability to generalize these findings to other Zambians residing in rural areas. Similarly, the sample consisted solely of female caregivers of children with DD, limiting the ability to generalize the results to Zambian men or adults who are not caregivers. Future research should explore the relationship between coping and executive function in a broader sample that is more representative of the general Zambian population.

Despite the issues noted above, this study demonstrates the resilience of many Zambian mothers and speaks to the need to address ways of reducing the use of negative coping strategies and facilitating positive experiences related to support coping. By incorporating consideration of a parent's executive functioning capacity, service providers may be able to direct parents towards coping interventions that will be more adaptive for them.

Study 4: Parent Experiences of Raising a Child with a Developmental Disability in Zambia: Respondent Elaboration and Contextualization of Prior Data

Several researchers have commented on the ethical issues that arise in cross cultural research. Milner (2007) describes truth - what is meaningful or real - as being dependent on how individuals have experienced the world. Some therefore argue that researchers always enter the field with biases, sympathies, assumptions, and (often privileged) positions within society that frame their research (Nygreen, 2006). For example, the researcher selects the measures or decides what questions to ask, which participants to include, and interprets, frames, contextualizes, and analyses the results (Nygreen, 2006). Despite increasing attempts to improve diversity, research conducted by Western researchers and through Western institutions continues to be largely informed by, and interpreted through the lens of, European Western values, ethics, and norms (Marshall & Batten, 2003; Ndimande, 2012). Research suggests that marginalized and ethnic minority participants frequently report feeling misunderstood by researchers from Euro-American culture and there can often be an incongruence between the researcher's views or theoretical framework and those of the research subjects (Arriaza et al., 2015; Marshall & Batten, 2003). Nygreen (2006) and Arriaza and colleagues (2015) argue that the power dynamics are further exacerbated by the fact that researchers typically occupy multiple positions of power in relation to research participants. Yet, unfortunately, the researcher is often not accountable to the communities that have been studied, resulting in an unequal relation of power that reflects and reproduces a colonial-like relationship (Nygreen, 2006).

Awareness of these issues has led to considerations about how to ‘decolonize’ research by attempting to disrupt, rather than perpetuate hegemonic assumptions (Ndimande, 2012; Samaroo et al., 2013). Decolonizing research involves critically examining underlying assumptions that inform the research and challenges Western assumptions in research (Samaroo et al., 2013). Samaroo and colleagues (2013) propose that accountability – inclusion of the voices, histories, cultures, and needs of the research participants – complements and strengthens the possibility for respectful research. ‘Respectful research’ refers to an approach in which the voices of participants are considered expert. In ‘respectful research’ the research process is considered transformative for both researchers and participants within a shared a cultural context (Tilley, 1998).

One method of attempting to rebalance power is by sharing research results and interpretations with participants and offering them the opportunity to share their perspective and correct misinterpretations. For example, in a member checking research process, analysed interview data is returned to the interviewees in order to allow them to validate, verify, or assess the trustworthiness of the results (Birt et al., 2016; Doyle, 2007). The member check allows the people who provided the information to determine if the researcher has accurately reported their stories (Koelsh, 2013). By re-engaging with research subjects in this way, researchers have opportunities to absorb unforeseen feedback and to adapt to new perspectives, hopefully resulting in a more accurate final result (Caretta, 2016). The member check acts as a means of triangulation – combining two or more methodological approaches or data sources – in order to increase the ability of the researcher to accurately interpret the findings (Thurmond, 2001).

Creswell and Plano Clark (2007) propose that mixed methods procedures with triangulation balance the weaknesses inherent in one method (i.e., quantitative vs. qualitative) with the strengths of the other and that, by allowing for the use of qualitative results to aid the interpretation of quantitative results, mixed methods designs have the potential to result in more accurate interpretations. There are a number of different means of obtaining both quantitative and qualitative data in a mixed methods design, including individual interviews and questionnaires such as those used in this dissertation. Focus groups are another commonly used approach; and are one way of allowing participants to provide feedback on data they previously provided to researchers.

Focus groups encourage the formation of more complex viewpoints through interactions between participants and may promote a sense of community and empowerment among participants. They also have the potential to encourage participation from people who are reluctant to be interviewed on their own or who feel that they have nothing to say (Wilkinson, 1998). In contrast to individual interviews, focus groups also capitalize on the interaction between and among participants to stimulate and refine thoughts and perspectives (Owen, 2001). In this way, the participants' interactions amongst themselves reduce their interactions with the researcher or interviewer, leading to a greater emphasis on the participants' perspectives (Wilkinson, 1998). Wilkinson (1998) points out that these interactions between participants also tend to generate ideas or perspectives that are more clearly articulated. Additionally, focus groups often result in positive interactions amongst participants, and participants typically enjoy their discussions together, thereby having a positive experience of the research process (Wilkinson, 1998).

Unfortunately, the original design of this overarching project did not explicitly consider ways to engage in respectful or decolonizing research methodology. In analyzing and interpreting the results of Study 1 and Study 2, I began to consider more deliberately the ways in which my life experience and Western educational background could have an impact on my interpretations. I was born and raised in Zambia; however, I was largely educated in Canada, and did not share the experience of parenting a child with DD. Therefore, it was important for me to consider the ways in which my experience and worldviews have been shaped by Western perspectives and may influence my interpretation of the results. To remedy this, the present study built on the overall project by sharing select results from Study 1 and Study 2 with a subgroup of the original participants in a focus group format, in order to ensure that my interpretations fairly and accurately represented their perspectives, and to allow them to expand on topics that I felt needed further clarification. Similar to a member checking process, I hoped that inviting feedback from participants would lead to greater accuracy in my understanding of the experiences of these parents and respect the contributions that the parents made to this project. The addition of the focus group to support the interpretation of the prior results follows the design of a mixed-methods sequential explanatory design – where qualitative data collected at a later stage of the research process are used to help explain and elaborate on the data that were collected previously (Ivankova et al., 2006).

Method

Participants

Participants were a subsample of 10 Zambian caregivers of children with developmental disabilities (DD) who had previously participated in Study 2. In selecting participants to participate in the focus group, I attempted to select participants with a diverse experiences and educational and economic backgrounds. I also attempted to select participants who I felt would be comfortable speaking in front of a group. All focus group participants were fluent in English, but some participants provided responses in a mixture of English and local languages, as is common practice in everyday conversation in Zambia. With the exception of one person, the participants were biological parents to the child (eight mothers and one father). The remaining participant was the child’s grandfather. Two of the participants were male, and the remainder were female.

Procedures

The focus group was conducted in December 2018, approximately one year after the data for Study 1 and Study 2 had been collected, and following analysis of the results. It was held in a private room in a local school and was approximately 120 minutes in length. Participants were provided with food and beverages and received an honorarium of approximately $10 (provided in local currency). Informed consent, including consent for audio recording, was obtained from each focus group participant (Appendix F). Further, all participants agreed to maintain the privacy of other parents who were participating in the focus group.

Following the analysis of the results from Study 1 and Study 2, I developed a focus group discussion guide (Appendix G) that was designed to explore parents' impressions of key findings from Study 1 and Study 2 and expand on any topics that needed clarification. Parents were invited to share their impressions of select results that I found particularly interesting or surprising or felt needed further clarification. Parents in the focus group were explicitly invited to share their perspectives on some of the results (i.e., "I just wanted to discuss with you some of the things that I found so I can hear your opinions"). As data from Study 3 was collected around the same time as the focus group, results from that study had not yet been analyzed and that data was not included in the focus group discussion. An example of a question that was posed to the focus group is: "most of the women who were married said that they were very happy in their marriages. What do you think helps a marriage stay happy when you have a child with such challenges?".

Analysis

The focus group was audio recorded and then transcribed verbatim. As in Study 1, an inductive approach was used to analyze the data. The transcript was reviewed several times and impressions and other comments were then made throughout the document. The text was then re-read, and the emergent framework was used to group the data. Thematic analysis was applied to synthesize the notes into more specific themes. Repetitions in the data within each transcript and across different transcripts were used to establish themes, as recommended by Ryan and Bernard (2003). The transcripts were then re-read to identify direct quotations that were particularly representative of each theme. Similar themes were then clustered together, and clusters were given a descriptive label that communicated the nature of the theme.

Results

Overall, eight main themes emerged from the focus group discussion: (1) financial hardship and women's employment, (2) marital satisfaction, (3) marital breakdown in the context of raising a child with DD, (4) educating fathers about prenatal and postnatal issues related to DD, (5) stigma, (6) acceptance of the child's condition, (7) medical care, and (8) school-related issues for children with DD.

Financial Hardship and Women's Employment

Similar to Study 1, parents in the focus group discussed the way financial hardship limited their access to services for their child. In the focus group, parents provided slightly more context to this theme; describing how they were not able to be critical about the services that they did receive, because they could not afford to access better services. For example, one father provided this example:

> So the aspect of money … I think can really help most of us to take care of our children the way that we would want. It's like, it's like when we want to eat we say, "those people who are well-to-do they eat what they want to eat when they want to eat", but for us who are poor we eat anything because we just want to fill our stomach. To some extent that's how we treat our children because we are not able to give them exactly what we want.

The discussion also revealed that expenses related to disability led some women to consider employment even though it did not fit with the desires that they or their families had. For example, one mother said, "the setup here in Zambia, probably in Africa, is different from Canada because maybe there women (are allowed) to work by their husbands but here - especially in Zambia - you find that her husband is okay with the wife being just a housewife, he is okay with that". However, another mother pointed out that such marital arrangements limited the family's financial possibilities by preventing the mother from contributing as much to the household, financially, as the father. Additionally, she highlighted that this arrangement also limits the mother's economic freedom as she is not able to make financial decisions that her husband does not approve of:

> So the wife has to be a housewife and the husband has to be doing the running up and down. At the end of the day you find that the wife can do anything as much as maybe the husband can - provide whatever he can provide. But it doesn't meet. Because not everything that a man provides is for the wife's demand.

Finally, other mothers reported wishing to maintain employment for other reasons, even though their child's needs led them to feel pressured to stay home to care for the child. For example, one mother reported having to give up on her career goals:

> I used to operate a salon - I had my own salon and the experience I had was whenever I have a customer sometimes he [the child] would pick things, throw things away, and stuff like that, and then instead of concentrating on the customer's head and I would concentrate on the child. Sometimes I will just close the salon and come back home and stay home.

She reported disappointment about this, saying "I am a young girl, I need to uplift my goals also, finish up with my education … just to become something, someone in future, and this is the challenge at hand". Similarly, another mother said:

> For me, I wanted to work but also challenges with my child - because you know at (thirteen) the child is still in diaper and then also my daughter's got difficulties feeding … I've done this, I've finished my education and wanted to do this, but I can't find a job because I know I want to stay with my child.

Another mother reported viewing her time at work as respite for herself, saying:

> I just need some time out of home…sometimes I love outings if she gives me opportunity because I also need some time out. 24/7 we are together, we sleep together, we wake up together, we come back here together, we go back together, it's just together, together, together. I sometimes need time out.

Marital Satisfaction

In the focus group discussion, it seemed that marital satisfaction was more complex than could be captured in the single item rating used in Study 2. Most participants did not seem to have the expectation that "complete happiness" was possible; therefore, it is possible that ratings of "happy" on the questionnaire used in Study 2 were more akin to parents reporting being "content". For example, one father argued:

> I think It also depends on how you look at being happy. I think to me it's not having everything that we need for life but if my wife loves me and I still love her the way I love at first then of course we should be happy.

One grandfather shared, "there cannot be total happiness", while one mother said:

> I can say I'm 'happy' but with inverted commas. You know how marriage is. Marriage has got its own challenges and as they say, 'two trees that are planted together will always shake' so there is always that shaking … So there is part of marriages whether you like it or not will always have conflicts here and there. And there are happy times, sad times, because it is - we come from different backgrounds. We have grown from different families, so there's no total fully - how can I say it? - that 'total fully happiness'.

This mother went on to share that happiness within a marriage was more complicated for parents of children with DD, as the needs of the child trump the needs of the parent, thereby altering parental expectations related to marital satisfaction. She shared:

> I was thinking “if I leave this man then I have to go with my 3 daughters” - before I had 3 daughters – “then if I go with them how will I cope with this condition alone?” So I said “let me sit. I will stay in this marriage and work it out until it works, and if there is all those conflicts then we will learn how to put up with one another eventually as we continue raising up [child]”. Because - like in my case - because if it wasn’t - if I hadn’t had [child] I would have left that marriage a long time ago because being single is nice [laughs].

She went on to share that marital satisfaction is further complicated for women in Zambia due to patriarchal expectations within the marriage, saying:

> But when you get married - as for us women - you always have to subject and subjection comes in when you have to give in a lot of things because if you want to do things he is going to say “no”, and you feel like “[sigh] I really wanted to do that but he says ‘no’”… And if you don’t do that then you’re conflicting now - “you don’t want to listen to me. you don’t have respect for me” - there is all that kind of issue. But if if if the man is more understanding … it makes things easier because then you will be able to work things together, unlike when a man starts commanding you … So basically, marriages are nice when one is strong enough to handle the challenges. There are a lot of challenges.

Marital Breakdown

The discussion revealed that some single mothers felt that their ex partners had left the relationship due to the child’s disability. One mother said, laughing,

> Yes! And they're leaving nicely, *ka*? Good! Like "hey, this is your child, my dear. Let me go and find another woman" – me, I was even told like that – "mama, this is your child. Let me go and find another woman who is going to give me another child who is going to do what other children are able to do at 9 months."

Another single mother shared that her husband left her because he considered the child's disability to be proof of her infidelity:

> I will narrate from my own own experience. Me, the father of my child left me because of the child's condition. He said it to my face. He said "*su' umvela*" ["you misbehave"] - like "I've heard you're sleeping around with other men that's why your child has become like this". Of which it wasn't even the case.

One single mother shared the belief that this trend was more rampant among young couples:

> From my own observations - I've observed to say fathers - those that experience disability - maybe to the first borns - usually they leave us. Because when you take the consideration of single parents it's us young ones! Because those that have been married and those that have children before raising a child – or before giving birth to a child with a disability, they stay and they're still together. But for us, first born child, as soon as they realize to say the child has disability they will surely leave us!

A father suggested that the perceived trend of young men abandoning their families may have been related to fear about the financial burden of raising a child with a disability, rather than stigma related to the disability itself. He said:

> It’s more to do with the responsibility because even even able-bodied children sometimes they are neglected because this young man doesn’t know how he is going to support this child and the mother. So sometimes they refuse the pregnancy based on the responsibility. What about this child who is not able-bodied?

Finally, one single mother in the focus group lamented that, even though her child’s father claimed that the child’s disability was not the reason he left, the support she received from him was only financial in nature and he avoided seeing the child:

> On my behalf, although he denied that no he did not leave me because of the child, he supported the child but never saw her … He would definitely support the child. Anything, medically, whatever I needed for the child he supported but never saw her and … when I ask … he says “no, I’ll just send the money”. He … thought the money would - money was everything so my presence wasn’t - or his presence wasn’t needed at all.

Education for Fathers

Some parents reported feeling as though the attitudes of fathers towards children with DD could be improved with increased access to education and counselling for the fathers. Both men and women alike agreed that this was an issue. For example, one mother shared her frustration that the burden of sharing the information with fathers fell on the mothers, who were the only ones expected to receive the information about child development:

> On the other side, I’ve noticed, there is no more counselling to the parent because us when we are pregnant we attend antenatals and even after giving birth at least we go to clinics more often compared to fathers of the children. So if there is something like counselling done to the parents of- or especially fathers - that would have brought maybe more acceptance and more

> knowledge… There is no one to explain much - they all depend on information from us women only… Now whatever information we are given we bring the information, and sometimes maybe they misunderstand us.

Men are free to attend such clinic visits with mothers and a father in the focus group shared that he had made a point of attending visits with his wife in order to remain informed about the child's condition; however, many parents in the focus group (both men and women) expressed that this was not the expectation of men and not the norm. One mother therefore suggested that men may need to receive the information through other means:

> So maybe if there was another form of educating our men in this country to learn about certain things because like disabilities of our children they are things that they can learn to understand – they are not very difficult to understand and if men learned about the disabilities of different children maybe that way they would be able to be more supportive and more understanding of the child's condition.

A father in the group shared his agreement, saying "when it comes to education - sensitization on how these conditions come about - I think the men-folk are left behind when it comes to this".

Stigma

Parents in the focus group went on the share that stigma in the Zambian community at large led to some parents isolating their children within the home. For example, one parent said:

> Some I would say they feel embarrassed to let the people know that they have a child with disability so they decide to have a maid - maybe they leave you with the maid at home they don't want to know they have a disability child.

Stigma and parental shame about their child's disability was thought to negatively affect the child by leading to the parent spending less time with the child. One mother expressed her feelings about the issue in this way:

> If they can neglect those normal children that they have, what more for a special child because these children we are told we need to have time with them, show them affection. Because for them to grow and to learn some of these things they need to feel that love from us … Basically all they are doing is spending money for that child and not showing the love and attention that the child deserves … [It] comes back to not having the love for the child, not having enough time just to find out what your child needs. Even just learning a few things that would make a child feel better.

Acceptance

In the focus group discussion, many parents discussed the importance of acceptance but alluded to it being a complex concept. When asked to define acceptance one mother described it this way:

> I take [child] just like any other of my daughters. I don't separate or treat her in special way or mistreat her in any way. So, basically accepting means just treating her like a normal child that is my own understanding.

Other parents provided similar definitions, while some others offered different interpretations. One father described it this way:

> I was thinking, I think accepting is more to do with not thinking that this person is to blame for the condition - or you, the parents. So it's not because of the child, it's not because of you but you have this situation that will remain with you and because it will remain with you, you have

> to accept it in that sense. So, accepting is not blaming this one or that one for the condition but saying, “we will handle it. God has allowed it to be part of us”.

Still other parents shared their belief that there was no such thing as “total acceptance”. For example, one mother shared this metaphor:

> There’s no total acceptance that’s what I’ve come to believe. Why? Because, there is – it’s like a sore that has got a scar. Every time you look at the scar it reminds you of the cause. Every time you look at the scar it reminds you of the cause - it reminds you of whatever you have gone through.

Finally, some parents provided the distinction between accepting the child and accepting the child’s condition, or the problem behaviours that accompany the condition. For example, one mother shared:

> We love them. We have accepted them. But the package that has the condition - that is not really - not okay. We cannot accept it because still *papaing* my daughter - still putting her on my back - even at 10 - I will not say “it’s ok”. I get tired! I’m human!

Similarly, one grandfather shared:

> I think this word ‘acceptance’, we accept that the son or daughter belongs to you but the effect that child – maybe through this behaviour – the child is behaving “what and what”. That’s the problem.

The same grandfather shared the way he felt religious faith promoted acceptance, saying “if you go to Bible principles it is said that the child is gift from God so … whether disabled or abled, but all children are a child of God – these are some of the principles”.

Medical Care

Many parents reported frustration with the medical system with parents expressing a perceived difference in quality between public and private hospitals. For example, one parent responded: “your question was ‘what’s the difference between those who are happy with the hospitals and those who are not’. Well, unless they tell me they go to private - but the government ones I think the general feeling I have is that they don’t do their work.” Another mother added: “they keep on changing doctors”. In public hospitals, the lack of continuity between physicians was a factor that seemed to impact the quality of care the families received. For example, one mother complained:

> I don’t sleep, my daughter doesn’t sleep (there was only one good doctor used to give us the medication for her to sleep) so when I went back to [the hospital] - tried to find out what they can use for her to sleep, I didn’t find the medicine up to this date. So, I don’t sleep, she only sleeps two hours.

Wait times at the hospital were another complaint: “I think it’s [doctors] to attend to people but you have to look for them. Even when you tell them your problem, they are so reluctant to the point where sometimes even the condition gets worse at the clinic itself”. Parents complained of wait times despite many of them having the understanding the children with disabilities were supposed to have special provisions at the clinic so that they did not have to wait as long: “yes, even when there is a law saying that special child shouldn’t be on the line even when you find a line you go and see the doctor they come out but that’s it … every child, special child should go straight to see the doctor”. Additionally, parents complained that, even when the child was seen, doctors sometimes seemed to lack understanding about disabilities and are so busy that they do not have the time or patience to spend trying to determine the cause of the child’s complaint. For example, one mother complained of the challenges of taking a nonverbal child to the clinic:

> You know these children they don’t come with menus - most of us don’t know if the child is [sick] but we also don’t know, but [we] keep guessing because most of them are not verbal. It’s this: you trying to assess, you just keep guessing, you don’t even know. Even as mother you don’t know but keep guessing. But you take that child who has been crying the whole night and whole day [to the clinic] - trying to say “maybe the child may stop crying, the child may stop crying” but the child doesn’t stop crying. Taking that child to medical personnel, “my child has been crying maybe the temperature … maybe she is not comfortable … maybe she has headache” … they don’t really do their - they are maybe too busy with their work. Maybe they want to attend to as many patients as they can so they don’t give us much time.

Another mother complained that some medical professionals still used terms like “brain damage” that some parents found offensive:

> I get upset - ‘brain damage’ - anything that is damage you throw because it’s useless. Explain to us what is [cerebral palsy], what are the causes of this? Nothing is explained in the hospital.

Finally, one mother shared that, even when information is shared by medical professionals it is not always in language that can be understood by the parents and, as a result, parents may give up on trying to obtain information from the medical professional. This parent further suggested that, such communication barriers may disproportionately affect parents who may need the information the most:

> And the other thing again is just like knowledge - you know. This is a mother that has never been to school and then they show you this and you don’t understand anything about - you know nothing. They explaining medically, there are big words, that you don’t even understand … They can explain it – teach, I mean - Zambian women whatever in local languages they understand… Now if you say it in English, in very big words that you don’t even understand, even if they are taught - because language is also a barrier… - even if they are taught we do not understand. Also

> that also becomes an issue. The doctor and the client they cannot get along because of big big languages that they have studied in their books. No, “this is whatever” …okay, and then when you go home, “what did they say?” … You just say “okay whatever” - you live like that. So language is also a barrier with someone that has never been to school. It’s very hard. And you know you find that, with disabilities, those [who] have never been to school, they are the ones producing more, that’s how I look at it, they are producing more children.

School

One parent shared that seeing any progress that her child made left her satisfied with the school: “because my daughter is improving each time and teach her new things and she comes home with experience in those things”. The only specific complaint about the educational system expressed during the focus group discussion, was the lack of widespread or accessible vocational training for children with disabilities. For example, one mother said:

> I want the child to learn at least certain skills, maybe even making small basket, even just mending a shoe. Most skills that they can learn - because children with disabilities have got different talents we don’t even know them even ourselves as parents. But, when they get there - those people with right training - they can do something.

Overall, parents in the focus group expressed that their child’s level of impairment affected their feelings about their child’s educational prospects, above and beyond their school experience. For example, one mother compared her daughter to other children with disabilities, saying:

> She is not talking - she can’t to do some other skills because she is dependent on me hard to sleep and other stuff. I want her to reach like other children. Even just to sew something - if she was normal she was able to sew and go sell and find something for herself. Now such a child

> that cannot learn or just sleeps, [it] is really hard for them to do these skills and other stuff. For me, I would really want my child to learn skills for - but looking at disability that the child has I have no hope for anything.

Discussion

The focus group was successful in providing parents with the opportunity to share their perspectives on the results from Study 1 and Study 2. Parents appeared to feel comfortable sharing their opinions about results that they agreed and disagreed with and the results of the focus group provided valuable insight into the experiences of parents of children with DD in Zambia.

The results of Study 1 and Study 2 established the significant impact that financial need had on the lives of parents of children with DD in Zambia; however, the focus group discussion added further context to that information. For example, parents talked about how they could not be as selective as they might want to be about the specialized services that their children received due to financial restrictions. The focus group discussion also highlighted the fact that our assessment of employment in Study 2 did not fully capture the nuances of women's experiences in Zambia. For example, parents reflected on how cultural norms in Zambia resulted in some men preferring their wives to not seek employment outside the home, despite the family's financial insecurity. Similar to mothers of children with DD in other countries, however, Zambian mothers who wanted to work also reported being limited by their caregiving role (Gordon et al., 2007; Yantzi et al., 2007). Employment limitations were judged to restrict financial freedom for single parents or women who did not have supportive husbands. Additionally, mothers reported wanting to work for reasons that went beyond financial incentives, such as a desire for fulfillment or simply a desire to have a reason to leave the home. This is important as research has found paid employment to be associated with better mental health for mothers of children with DD in particular (Einam & Cuskelly, 2002). Importantly, however, research by Eisenhower and

Blacher (2006) points to the strong moderating role that financial hardship may have in this relationship. Specifically, they found that mothers who were unmarried *and* unemployed demonstrated markedly diminished well-being while mothers in the other groups (i.e., unmarried and employed, married and unemployed, married and employed) demonstrated comparable well-being to one another (Eisenhower & Blacher, 2006). Overall, the results of the focus group provided further context to the complex relationship between financial hardship, employment, and marital status for mothers of children with DD in Zambia.

The present study also highlighted factors that may have contributed to parent ratings of their marital satisfaction in Study 2. The high ratings of marital satisfaction in Study 2 were particularly surprising given that research in other countries suggests that parents of children with DD, such as autism spectrum disorder, report lower marital happiness (Higgins et al., 2005), marital adjustment difficulties (Lickenbrock et al., 2011), and less sense of consensus in the marital relationship (Oelofsen & Richardson, 2006) than parents of typically developing children. The results of the focus group discussion indicate that, among Zambian parents of children with DD, there may not be an expectation of “complete” happiness in marriage. For these parents, their benchmark of happiness seemed to be lowered to what they perceived to be a more realistic standard. Another mother offered the perspective that, for women, marital satisfaction was more related to one’s ability to overlook or withstand the challenges that inevitably accompany marriage. Consistent with this sentiment, Mwape and colleagues (2012) report that “a sense of endurance is commonly inculcated in women in Zambia. A strong woman is one who possesses the ability to withstand problems in her marriage, including extramarital affairs by her husband” (p. 7). Finally, for women in this study, societal expectations about female subjugation, and the degree to which one’s husband was understanding or supportive of a wife’s needs, also seemed to play a role in their satisfaction. This is consistent with cross-cultural research by Rehman and

Holtzworth-Monroe (2007) suggesting that marital communication is significantly related to marital satisfaction across various cultures.

Single mothers in the focus group seemed to share the perspective that their relationships had dissolved because of the child's disability. Some parents reported that this had been explicitly stated to them while others reported that they came to this conclusion because of their ex spouse's behaviour towards the child. One father ventured that some fathers who left their partner and child due to the child's disability, may have done so from fear of the financial commitment and the pressure to provide for the family, rather than because of stigma related to the disability. He proposed that fear of commitment and financial obligations were pressures that many young men experienced, and the financial obligations and needs were perceived to be greater for children with DD, resulting in a greater frequency of abandonment. Indeed, Mwape and colleagues (2012) found that anxiety related to abandonment by one's spouse was common for women during the perinatal period, even among mothers who did not have children with DD. For women who did not have children with DD, it was assumed that the reason men deserted their spouses was due to the shift in women's focus of attention and care from their partners to their children, which resulted in men feeling neglected and seeking affection outside their marriages (Mwape et al., 2012). Importantly, Mwape and colleagues report that low-income women were particularly susceptible to increased psychological distress related to fear of desertion.

Parents in the focus group suggested that providing education for fathers may help reduce the frequency of fathers abandoning their families following the birth of a child with DD. Parents reported that a key point of education for mothers was through antenatal and "under 5" clinic appointments, where they were provided with counseling and education about DD. Parents reported that there was no expectation for fathers to attend such appointments and the majority did not do so. As a result, the burden of sharing information provided at these appointments fell to mothers. One mother ventured that an effort needs to be made to educate fathers specifically, through a different means than antenatal appointments. Research by Diemer (1997) and by Sahip and Turan (2007) supports the idea that men may benefit from parent education tailored to fathers, specifically. Diemer (1997) proposed a conceptual framework for evaluating the effects of educating expectant fathers on spousal relations that suggested that participation in 'father-focused' discussion classes would decrease stress, increase coping skills, and increase social support for fathers. Indeed, in a sample of fathers in the United States, the male-focused training programme was more effective than a traditional programme (Diemer, 1997). Sahip and Turan (2007) based their study on fathers in Turkey on a similar conceptual framework. Similar to the assertions of parents who participated in the present study, Sahip and Turan (2007) reported that fathers in Turkey displayed reluctance to attend antenatal and postnatal appointments with their partners. They found that a physician-lead program, provided in the father's workplace, was an effective means of providing parenting education to fathers in Turkey and resulted in an increase in positive maternal-child health behaviours by the father (e.g., supporting good nutrition for the expectant mother and for the child). Additionally, participation in this "father-focused" program also lead to an increase in attendance in antenatal and postnatal appointments. These studies suggest that, providing parent education specifically for fathers, may result in better education and parent involvement amongst fathers of children with DD in Zambia. Improving fathers' understanding of DD and their involvement in caring for the child may decrease conflict in the marital relationship, as well as improve the father's acceptance of the child with DD.

The focus group also highlighted parents' different interpretations of what it means to accept the child with DD. Spousal desertion was interpreted by some mothers as a lack of acceptance of the child, as noted above. Similarly, some parents reported that, despite receiving financial support from their spouses, a lack of emotional support or engagement with the child was perceived as a lack of acceptance of the child. For mothers like this, a single overall “helpfulness” rating, such as the one used to assess spousal support in Study 2, may not be sufficient to capture the complexities of the type of support the spouse provides, and what support needs are remaining unmet. The concept of acceptance primarily came up in Study 2 through the assessment of coping strategy use. The focus group discussion suggested that more research is needed in order to understand the complex ways that Zambian parents reconcile what it means to accept their child with DD, and which interpretations of “acceptance” facilitate positive coping outcomes. Additionally, it suggests that researchers wishing to examine “acceptance” as a coping strategy or treatment target may wish to consider using more precise language and clear examples of the specific coping behaviour being examined.

Similar to Study 1, but in contrast to Study 2, many parents in the present study reported dissatisfaction with the medical care they received. In Study 2, few parents endorsed having regular access to a physician, but the majority reported satisfaction with the healthcare that their child receives. These discrepancies highlight again the challenges in rating satisfaction on a single item scale in the present sample and suggest that, in future studies, it may be important to use different language or more precise questions to evaluation satisfaction. When medical care was explored in the focus group, parents reported a discrepancy between public and private clinics, complaining that public clinics had long wait times, lack of continuity of physicians, and a lack of awareness of the needs of children with DD and their parents. In a study conducted at a child development centre in Israel, parents’ satisfaction with the care that their children with disabilities received was significantly correlated with the three dimensions of physician communication measured: collaboration, caring, and interest (Galil et al., 2006). Additionally, collaboration between the physician and the parent (e.g., mutual decision making and sharing of responsibility) significantly contributed to the variability in parent satisfaction in that sample (Galil et al., 2006). Research on physician-parent communication with parents of preterm infants also found that parents wanted physicians to be sensitive, compassionate, use limited medical jargon, and provide realistic and truthful information (Kharrat et al., 2018). It is likely that increasing the degree to which physicians checked in with parents about their recommendations, and used lay language, would serve to improve parent satisfaction with the services they were receiving and may improve compliance with medical recommendations. Indeed, an important finding in the present study was that parents felt that often information was not shared in language that was accessible to many parents and that, rather than ask for clarification or endeavour to decipher the information, parents may simply give up. In considering barriers to medical care for children with DD and their families, it is also important to consider, as reported in Study 1, and as is common in other countries as well (e.g., Fenton et al., 2003; Wilkinson et al., 2012), Zambian doctors face a number of challenges in the workplace and experience a high amount of stress (Menon et al., 2007). This stress, coupled with low levels of education about DD (Chansa-Kabali et al., 2019), makes it more difficult for physicians to provide adequate care to children with DD and their families. Therefore, increased support and training of medical professionals will also be essential in helping alleviate challenges faced by children with DD and their families in Zambia.

Finally, many parents in the focus group expressed an interest in vocational training to allow their children to learn practical skills that they may be able to use to support themselves. A few studies exist outlining vocational training programs for individuals with DD in other countries. For example, a training program in Canada trains young adults with intellectual disabilities in a number of service and clerical jobs, such as filing documents, folding laundry, or making a hotel bed. However, while the young adults receiving training at the centre enjoyed their time there, vocational opportunities remained limited (Butcher & Wilton, 2008). The authors therefore suggest that vocational training programs for individuals with DD be evaluated by, and valued for, their potential to provide meaningful activity and social interaction for individuals with DD outside the home, rather than using the acquisition of paid employment as the only metric of success (Butcher & Wilton, 2008). A vocational training program in Brazil adopted the approach of training participants for a specific employment opportunity, and involving a family member of caregiver in the vocational training of the individual with DD so they would be able to maintain the vocational support for the individual on an ongoing basis, as needed (Gomes-Machado et al., 2016). Gomes-Machado and colleagues (2016) found that, once the individuals with DD were employed, they were able to maintain employment at least one-year post-training, with a decrease in their need for support. Similarly, in an Australian sample, Cavanagh and colleagues (2019) found that opportunities for individuals with DD to participate in the labour market were driven by management staff and that, when given the opportunity, individuals with DD were productive and successful staff members. The authors argue that workplace interventions are needed to promote the inclusion of individuals with DD in more organizations (Cavanagh et al., 2019). Overall, the results point to the feasibility of increasing vocational skills among individuals with DD in Zambia with training but suggest that employment outcomes following such training will largely be dependent on the workplaces being open to supporting the involvement of individuals with DD in their labour force. Promoting awareness of DD in Zambia and reducing stigma may help increase the willingness of employers to include individuals with DD in their workforces.

The use of a focus group to validate our interpretations of the results and provide a deeper perspective on our findings was judged to be an effective means of critically re-examining our prior assumptions. The parents had not participated in a focus group before; however, they responded favourably to the process and expressed appreciation for the explicit guidelines around confidentiality and respecting the privacy of others in the group. Anecdotally, many parents reported that having this conversation about confidentiality and privacy at the outset of the group discussion put them at ease about being vulnerable and open within the group. Participants also expressed interest in research methodology and appreciated being involved further in the process. At the end of the group discussion, many parents spontaneously expressed how therapeutic the process of participating in the focus group had been, and some parents reported that they had found it valuable to hear the opinions of others that differed from their own. In this way, it seemed that the focus group not only provided an invaluable benefit to me as a researcher, and to the validity of the data, but was also judged to have sundry benefits for the participants themselves.

There are some limitations to the present study. For example, the group conversation that ensued between participants sometimes made it difficult to follow up on conversational leads to elicit additional information in a way that would possible through an individual interview study design. It is also possible that some people with differing opinions from others may have felt uncomfortable voicing a minority opinion in a group setting. I stressed to participants the value of their unique perspectives and that there was no “right” or “wrong” way to feel or think about the issues discussed; however, some people may have still felt uncomfortable with what they may perceive as disagreeing with or criticizing others. Additionally, for some people, the idea of having to speak in front of a group may have been more anxiety-provoking than an individual interview would have been. The focus group interview could also have been affected by selection bias. I selected participants who were fluent in English and who I thought would feel comfortable participating in this format of data collection. Therefore, I may have left out participants who may have had different perspectives than the people included in the discussion. Similarly, although I made efforts to put participants at ease, my presence in the room functioning as a moderator and potentially being perceived as an “outsider” may have impacted participants’ responses. Finally, the topics raised for discussion were based on items that I felt needed further clarification. Due to time constraints it was not possible to discuss the results of Study 1 and Study 2 in their entirety. As a result, some topics that may have benefited from inclusion in the focus group discussion may have been missed. Despite these considerations, this study provided valuable insights that enriched the understanding of the data collected in Studies 1 and 2 and contributed significantly to my understanding of the experiences of Zambian parents of children with DD.

General Discussion

In this dissertation I set out to explore the experiences of Zambian mothers of children with DD with a goal of providing direction for intervention and service provision. Using the Perry Stress Model (2004) as a framework helped make my examination of parent's experiences more comprehensive and I made an effort to ensure that I was capturing parent's experiences across each of the various domains (stressors, resources, supports, outcomes). Additionally, the model's explicit focus on both positive and negative outcomes helped ensure that parents positive experiences were valued as well. The model was easily applied to parents in Zambia, despite the cultural differences between Zambia and the North American context in which the measure was developed. The domains are broad and flexible enough that factors that may not be significant within one context can still be easily situated within the model in a different context.

The results of the four studies highlighted a number of challenges for parents of children with DD in Zambia but, as intended, also provided direction for improvements. Specifically, the results suggest that, at an individual level, certain personal resources and coping styles are associated with more favourable outcomes. Therefore, providing parents with the direction and tools to engage in more beneficial coping strategies will likely help parents better manage daily stressors. Additionally, increasing access to mental healthcare will help ensure that parents have the resources they need to be most effective. At a broader systemic level, the results of this dissertation also indicate that educating fathers about DD, and increasing knowledge about DD amongst healthcare providers, religious leaders, and teachers will improve the supports available to mothers of children with DD. Further, my findings suggest that efforts to combat poverty and increase financial independence for individuals with DD and their mothers will have far reaching implications. Finally, this dissertation highlighted the resilience of Zambian parents of children with DD, the vast majority of whom described experiencing positive impacts related to raising a child with DD alongside the challenges. Recognizing that my suggestions are likely influenced by Western norms and expectations, I offer them with respect in the hope that they can provide some benefit to stakeholders and policy makers seeking to improve the experiences of Zambian parents of children with DD.

Targeting Personal Resources and Coping Strategies

The results of Studies 2 and 3, in particular, suggest that there is significant potential for personal resources to mediate the relationship between stressors and outcomes. For example, the results of Study 2 suggest that empowering parents and promoting greater self-efficacy, will lead to better quality of life for parents, and more positive perceptions of their experiences with their children. Mothers described the use of various coping strategies in Study 1; however, the results of Studies 2 and 3 suggest that not all coping strategies will be equally effective (or feasible) for all parents, and some strategies may provide some relief from emotional distress in the moment but are related to negative outcomes. For example, some mothers in Study 1 described using strategies such as behavioural disengagement; however, the results of Study 2 suggest that use of negative coping strategies (including behavioural disengagement) was significantly predictive of poorer outcomes in this sample.

Active coping is generally associated with better responses to stressors; however, active coping strategies are also more cognitively demanding, and the results of Study 3 suggest that parents with poorer executive functioning abilities may have more difficulty effectively engaging in the use of such strategies. For these parents, use of other positive coping strategies, such as support seeking, may lead to better outcomes than the use of negative coping strategies. Indeed, the results of Study 2 indicated that having a greater number of sources of social support (formal and informal) was significantly related to having a higher quality of life in this population.

Taken together these results suggest that parents will benefit from being encouraged to avoid the use of negative coping strategies, such as behavioural disengagement, denial, and self blame. When possible, for parents who have the capacity to utilize them, active coping strategies such as actively seeking solutions to problems, planning, and acceptance will likely be most effective. For parents who do not have the capacity to engage in active coping strategies – perhaps due to limited executive functioning – support seeking strategies will likely lead to better outcomes than engaging in negative coping strategies. Research on interventions to promote coping skills for Zambian parents is limited; however, research on interventions for parents of children with DD from other countries suggest that cognitive behavioural therapy interventions, including coping skills training, may be effective at reducing stress levels and improving some cognitive functions (e.g., attention, memory, flexibility; Romero-Martinez et al. 2017; Singer et al., 2007).

Improving Access to Mental Health Care

It is not surprising, given the significant stressors that parents reported, that poor mental health - in the form of anxiety, unhappiness, loneliness, guilt, and stress - was a significant outcome for many parents who participated in this dissertation research. Unfortunately, similar to many countries, there are still barriers to accessing mental health care in Zambia. For example, despite the existence of mental health policy in Zambia, implementation remains poor, possibly due to lack of feasible plans and inadequate resource commitments (Omar et al., 2010). Further, research by Aidoo and Harpham (2001) found that Zambian women only considered physical symptoms such as headaches and heart palpitations as ill health, while problems of affect, such as unhappiness and suicidal ideation were considered “problems of the mind” but not ill health. Stigma towards such “problems of the mind” inhibited women from seeking psychiatric services (Aidoo & Harpham, 2001). Additionally, many women did not readily recognize stress and depression as health-related problems (Aidoo & Harpham, 2001). This research suggests that mothers of children with DD may not readily seek out support for mental health challenges even though the results of this dissertation indicate that mental health support would likely benefit many of these parents. Consequently, as suggested by Elafros et al. (2013), it may be beneficial for mothers to be screened for mental health challenges even when they do not volunteer information about poor mental health. Following their study on Zambian parents of children with epilepsy, Elafros et al. (2013) suggest that caregivers be screened routinely for symptoms of depression or anxiety when accessing healthcare services for their child. At that point, if warranted, parents can then be provided with resources or supports to help them manage those symptoms. Such screenings will likely be beneficial for a wide range of mothers; not just mothers of children with DD.

Increasing Awareness, Education, and Training in DD

The need to promote awareness of DD, enhance training for professionals, and reduce societal stigma about DD was raised by many parents in Studies 1 and 4 and indeed is not unique to Zambia. It is an unfortunate but widespread problem that negatively impacts the life experiences of individuals with DD and their families and limits the potential for society to perceive and benefit from the potential contributions of individuals with DD.

Educating Fathers

Parents in Study 4 also indicated that fathers of children with DD were left behind when it came to education about DD and one parent suggested that an effort needs to be made to educate fathers specifically, through a means separate from that used to educate women. Indeed, as discussed in Study 4, research on parenting programs specifically tailored for fathers have demonstrated favourable results in other countries and, in a sample of fathers in the United States, a male-focused training programme was more effective than a traditional programme (Diemer, 1997). Parents who participated in Study 4 suggested that educating fathers about DD may improve marital stability by shifting the blame of the child’s condition from the mother and helping fathers accept their children with DD. Educating fathers about DD may also result in fathers being better prepared to provide emotional support and having fathers involved in their children’s care may help relieve some of the burden of care from mothers.

Educating Healthcare Providers and Increasing Access to Healthcare Services

The results of this dissertation also highlighted the need to promote training in DD among healthcare professionals. In interviews conducted with mothers in Study 1 it seemed as though parents turned to healthcare providers for support with understanding their children's DD, as well as for medical care for physical ailments. Despite the potential for healthcare providers to function as a significant source of information and support, parents who relied on government-funded clinics (rather than privately funded clinics) reported a lack of consistency in the physicians they saw, reported that many physicians seemed to lack knowledge about DD, and shared that physicians were often too busy to take the time that was needed to provide information to parents in an accessible way. Parents' perceptions are consistent with the literature from various countries and a recent study by Chansa-Kabali and colleagues (2019) confirmed that there is a paucity of knowledge about DD among medical students in Zambia. Chansa-Kabali and colleagues (2019) found that only 27% of medical students in their 3rd to 6th year of medical school had ever heard of autism. Additionally, of the students who had heard of autism, the majority reported hearing about it from sources such as television, print media, and radio, and not through their educational programs.

Overall, introducing some basic training on DD to medical students and other healthcare providers will likely have a significant impact in the future on the stress of parents of children with DD, the health of their children, and their long-term quality of life outcomes. For physicians who are already practicing, it may be useful to provide continuing education opportunities on DD, or to facilitate the production and sharing of publications or pamphlets oriented towards providing healthcare practitioners with important information about DD. In addition to a need for additional training, it may be necessary to also publicize and promote the use of tools such as short questionnaires, that are specifically designed to support assessment or diagnosis of need in individuals with DD. Such tools can help improve clinicians' capacity to quickly and efficiently obtain and share information relevant to diagnosis or intervention of DD when they are limited in their expertise on DD. For example, Mont and Loeb (2010) advocate for the use of measures such as the Activity Limitation Score and Participation Restriction Score to quickly and reliably assess the impact of public health interventions in improving the lives of individuals with disabilities. Magnusson and colleagues (2019) present a scoping review exploring the use of screening and diagnostic tools for identifying children with disabilities in low- and middle-income countries. As healthcare professionals are expected to provide services to clients with DD, it is essential that training programs address this gap and empower practitioners with the expertise to support individuals with DD and their families.

A lack of widespread expertise in DD amongst healthcare workers is not a problem unique to Zambia and some international research exists examining the efficacy of pre-service physician training and practicing physician retraining programs. For example, Barkowski and colleagues (2018) report on the effectiveness of a clinician improvement program in the United States designed to improve medical care for individuals with intellectual disabilities. Following participation in the program clinicians demonstrated statistically significant differences in knowledge and self-assessed competence related to treating people with intellectual disabilities. Raemy and Paignon (2019) describe the development and implementation of an intervention to improve medical care for individuals with DD at a specific hospital in Switzerland. Rather than outline a specific curriculum that may not be completely transferable to other settings, their study can be used as a model for how different institutions in different countries may be able to develop their own intervention to meet their unique needs. Whilst guidelines based on interventions that have already been piloted can be helpful, they may miss key elements of physician experiences in Zambia. One helpful approach to determining how to best increase clinician competency in working with individuals with DD may be to take advantage of the expertise of the physicians and other healthcare providers in Zambia who already do have expertise in working with individuals with DD.

These clinicians will likely be in the best position to provide guidance and direction for physician training programs.

Finally, along with other researchers, Chiluba and Moyo (2017) propose that a move towards increasing the number of community-based health workers in order to promote access to in-home health support may be beneficial. Following interviews with community-based rehabilitation workers in southern Africa, van Pletzen and colleagues (2014) suggest that the workers' knowledge and understanding of resource-limited communities may constitute an important local resource that may strengthen their ability to address the related effects of poverty and disability in developing countries. Increasing the number of community-based health workers with training in DD may help promote access to higher quality health services for this population and may significantly improve parent stress resulting from barriers to accessing healthcare. For parents of children with DD who struggle with access to transportation (e.g., if the child is not mobile) or whose children may struggle with the noise or chaos of a busy hospital waiting room, access to in-home services can be particularly impactful.

In seeking to increase the number of community-based workers to help support parents of children with DD, it is worth considering the option of training a subset of parents of children with DD across various regions. Parents who participated in this dissertation already reported relying heavily on other parents of children with DD for various forms of social support, including emotional, instrumental, and informational. Training and recruiting these parents into formal positions that would help them better support one another would take advantage of the strong relationships and shared understanding that already promote a strong sense of community amongst these parents. Additionally, employing parents of children with DD in order to support other parents of children with DD could have the twofold benefit of increasing employment for parents in this subgroup, as well as improving access to relevant services. Whilst providing this healthcare support, these parent community-based workers would also be able to provide other forms of support to parents, based on their personal experience as well as the training they receive.

Recruiting Religious Leaders as Allies

The majority of respondents who participated in Study 1 endorsed using acceptance and religious practices to cope and religious communities and religious leaders were frequently endorsed as a significant source of support. This finding was consistent with my expectations, given the importance of religion in Zambian culture (Mung'omba, 2008). Unfortunately, however, there remains a high degree of stigma towards individuals with DD and their families, some of which is tied to the presence of disability being seen as the consequence of religious misfortunes directed to the family (Mung’omba, 2008). As such, religious leaders may be particularly well-poised to act as allies and help combat stigma against DD by spreading accurate information and improving community attitudes.

Similar efforts have been successful in combatting the AIDS epidemic in Zambia. For example, Patterson (2013) proposes that some pastors have been able to mobilize their religious followers to address the disease by taking advantage of the existing church organizational structures, and by using frames that resonate with the religious adherents. African religious leaders are particularly strong allies as they are respected and trusted, able to use their charisma and personalities to motivate, and have access to prior experience with the community, knowledge of cultural traditions, and social networks that may be advantageous. Wiginton et al. (2019) found that collaborations between international organizations and faith-based organizations in Zambia have been helpful in implementing HIV-prevention programmes. They argue that providing scientific information to faith leaders takes advantage of this “trusted messenger” (the faith leader) and empowers them to embrace a responsibility to effectively engage in health issues, and to transgress cultural boundaries to the benefit of the population at large. Stekelenburg and colleagues (2005) also point out that that collaboration with traditional healers (including faith-based healers and spiritualists) increases the potential to support a greater number of people living in less accessible areas as these healers tend to be more “evenly distributed” geographically than formal health institutions like hospitals.

Educating Teachers and Improving Access to Education for Children with DD

Special education schools and teachers were one formal source of support that was consistently described positively by parents and parents in Study 2 endorsed high rates of satisfaction with their child’s school. Unfortunately, not all parents had access to special education schools due to a variety of barriers. Mainstream schools were not consistently described in the positive way that special education schools were; however, the excellent support that special education schools and teachers were able to provide to parents suggests that mainstream schools may be well-positioned to play an intermediary role if mainstream teachers and school personnel were able to receive some training related to DD.

Despite the introduction of free education to Zambia and the Zambian national policy on the formal education of children with special education needs (implemented in the 1980s; Serpell & Jere-Folotiya; 2011) children with special needs remain less likely to be educated (Miles, 2011; Malungo et al., 2018). Serpell and Jere-Folotiya (2011) outline the way that the special education policy has been limited by economic challenges and competing priorities for resource allocation. The government of Zambia has made some efforts to introduce special education services through special schools but Miles (2011) argues that the assumption that special education services can only be provided through separate and specialized services makes it far more difficult to promote broad improvements, given the under-resourced condition of the public education system in Zambia. Miles (2011) instead argues for mainstreaming or inclusive education, where students with and without disabilities can be educated in the same setting.

Research suggests that attitudes towards the inclusion of children with disabilities in mainstream schools or classrooms varies greatly amongst teachers in Zambia (Moberg, 2003). Teachers tended to be critical of inclusion and more biased towards segregation of children with “severe” disabilities, compared to those with “moderate” disabilities (Moberg, 2003). Similarly, although Muwana and Ostrosky (2014) found that pre-service teachers’ attitudes towards inclusion were positive overall, when disability groupings were examined more closely, positive attitudes regarding inclusive education tended to apply more to physical disabilities than intellectual disabilities. Pre-service teachers’ attitudes also differed significantly depending on their area of specialization (i.e., special education, primary, or secondary), their year of study, and how many years of teaching experience they had. Notably, participants with more than 10 years of teaching experience exhibited less positive attitudes towards inclusion (Muwana & Ostrosky, 2014).

Despite some teachers’ negative attitudes towards inclusive education, Miles (2011) provided evidence that attitudes may be improved through writing, discussion, and reflection. Further, such discussion and reflection may lead to collaborative action that helps address barriers to learning and inclusion. Moberg (2003) found that few teachers surveyed had experience with inclusive education and Muwana and Ostrosky (2014) suggest that some of the reticence regarding inclusive education may be addressed with increased support for teachers, retraining of general classroom teachers, and information about how the general education classroom procedures can be adapted to accommodate these students. As suggested by Malungo and colleagues (2018), it will likely be necessary and beneficial to increase training for pre-service teachers, as well as provide opportunities for continuing education of teachers who are already practicing. Overall, the results of Muwana and Ostrosky’s (2014) study are optimistic in that, despite raising significant concerns, many teachers acknowledged that children with special education needs have a right to be educated in the general education classroom and many also saw the benefit of inclusive education for students with and without disabilities (e.g., promoting understanding and acceptance of individual differences).

Increasing the capacity for mainstream schools to provide inclusive education and ensuring that all schools have access to information about children with special needs is important for multiple reasons. Building the capacity for mainstream schools to provide special education programs will help improve access to special education services for families who do not live near a special school. In addition to the rights of these children to be educated, schools and teachers were relied upon by mothers in this dissertation as a significant source of support. Mainstream schools may be the first place that children are identified as having special needs. As a result, they should at least be informed enough to be able to direct parents to appropriate services. With the appropriate information about DD, schools may be better equipped to identify children early and provide parents with direction on how to support their children. Finally, increasing the exposure of other, typically developing children, to children with DD at an early age may be instrumental in helping address stigma in the broader community. Indeed a pilot study by Nabuzoka and Rønning (1997) found that Zambian primary school boys who had been exposed to children with intellectual disabilities expressed more positive attitudes towards children with disabilities than boys who had not had any contact with children with intellectual disabilities.

The positive perceptions of special education teachers shared by parents who participated in this dissertation speak to the quality of special education training likely already being provided in special education training programs for preservice teachers in Zambia. It may be helpful for Zambian teacher training programs to consider ways to adapt the special education specialization into a training module on DD that can be incorporated into training for mainstream teachers. Similarly, as suggested by Malungo and colleagues (2018), it will likely be beneficial for Zambian special education teachers to work with mainstream teachers in order to improve education programs for children with DD in Zambia. It is worth noting that, in a study examining the preparation of mainstream teachers in Zimbabwe for the inclusion of children with disabilities in mainstream schools, Majoko (2017) found that several strategies used in conjunction with one another were beneficial. In addition to the infusion of disabilities and socio-cultural issues in the curriculum for educators, mainstream teachers were also trained in theory and practice related to inclusion, and stakeholders collaboratively pooled resources. Majoko's (2017) study suggests that facilitating teacher training in DD may require more than an expansion of the curriculum, but also provides a model of success in a similarly resourced and neighbouring nation.

Financial Supports for Children with DD and their Families

Financial difficulties were a significant source of stress for many parents and the results of Study 2 indicated that financial need is significantly predictive of poorer mental health and poorer quality of life in this sample.

Utility of School Access and Vocational Training in Combatting Poverty

Single mothers who participated in this dissertation were under further financial strain when they did not have family support. Lack of spousal or family support meant that these mothers shouldered the burden of financial provision alone, but had difficulty finding employment as they also struggled to find childcare. One mother in Study 4 suggested that if the government were able to improve access to special education programs (e.g., by providing transportation or increasing the number of schools equipped to support children with special education needs), mothers may be able to find paid employment outside the home during the hours that their children were being educated. Additionally, education is positively associated with access to employment for Zambian adults with disabilities (Trani & Loeb, 2012). In this way, increasing education services for children with DD can target poverty in this population twofold.

Many parents in the present study reported significant concern related to their children's future that were sometimes related to the child's inability to care for themselves. These concerns are not unfounded as Mung'omba (2008) found that a majority of adults with intellectual disabilities who were able to acquire life skills through programs run by NGOs still remained unemployed, even though the few individuals who were able to find employment tended to perform well. This is unfortunate as international studies suggest that vocational programs for individuals with DD are effective at supporting adults in this population in obtaining and maintaining gainful employment when they are provided with appropriate assistance (e.g., Fasching, 2014; Gomes-Machado et al., 2016; Lin et al., 2017). Research on vocational training and employment of individuals with DD highlights the potential for individuals with DD to contribute to society in a meaningful way. Malungo and colleagues (2018) assert that affirmative action policies promoting the employment of individuals with disabilities are one important way that individuals with disabilities in Zambia may be able to overcome systemic barriers to accessing employment. Importantly, however, optimal outcomes are received by providing access to appropriate supports for these individuals. Research by Petner-Arrey and colleagues (2016) suggests that parents and family members can also be a significant source of support and should be involved in the process of connecting with work options, negotiating job fit, and sustaining work over time. Scheef et al. (2019) suggest that a practical approach for vocational programs would be to start by identifying employability skills that certain employers value in order to ensure that these skills are being targeted in training for individuals with DD. Overall, this research suggests that improving vocational outcomes for individuals with DD is possible with some support. Further, such improvements are likely to have far-reaching implications. Beyond opportunities to generate income and reduce poverty, inclusion in the labour market improves the lives of individuals with DD by promoting learning, autonomy, affective and social development, and family and community relations (Gomes-Machado et al., 2016). Trani and Loeb (2012) also report a positive relationship between education, employment, and access to healthcare; an association that is particularly notable for people with intellectual disabilities in Zambia, who faced greater barriers to accessing healthcare overall.

Empowering Mothers through Financial Support Programs or Social Welfare Benefits

The importance of helping mothers, and single mothers in particular, meet their basic needs and those of their children cannot be overstated. Mothers in Study 1 indicated that some financial support was received from local NGOs; however, many single mothers were still unable to meet their basic needs. Results pertaining to single mothers are particularly poignant as rates of single motherhood in Zambia are high and children of single mothers, including typically developing children, tend to have less favourable outcomes than children in two-parent homes. For example, research by Clark and Hamplova (2013) found that the percentage of women in Zambia who will have a premarital birth is 26% and Zuilkowski and colleagues (2019) purport that adolescent pregnancy remains a major contributor to child mortality and cycles of poor health and poverty. Despite policy in Zambia ensuring that young mothers have the right to continue their schooling following a pregnancy, the study suggests that stigma and judgement result in young mothers leaving school and not returning. The study suggests that, while girls with knowledge of the policy were less likely to be forced out of school, the implementation of the policy often fell short of its potential (Zuilkowski et al., 2019), thereby resulting in these mothers being doubly disadvantaged in the job market by lower educational attainment and having to care for a child.

Research by Bonilla and colleagues (2017) and Hjelm et al. (2017) provides evidence of the potential that financial support programs have to reduce poverty and improve the lives of Zambian families of children with DD. Mung'omba (2008) found that social welfare benefits in Zambia tended not to be accessible to individuals with DD and, even though the government administers a trust for persons with disabilities, these funds are rarely accessible to those with developmental disabilities in particular. Such financial assistance would not only benefit single mothers who are at greater risk of poverty, but also empower married women in homes where men are the primary breadwinners. In research on Zambian families, Mwape and colleagues (2012) found that it was not uncommon for men living in their home to not be providing financial support to the family even though most women in the study were depending on their husbands for financial sustenance. It is not surprising then that research by Bonilla et al. (2017) found that a cash transfer program for parents of children under the age of 5 empowered female beneficiaries by allowing these mothers to exercise more control over household finances and savings for emergencies.

Parent Resilience and Positive Impacts of Raising a Child with DD

In addition to the valuable information gained regarding directions for intervention and service provision, the results of this dissertation also highlighted the strength and resilience of parents of children with DD. Many mothers who participated in this study were resourceful in finding ways to overcome financial restrictions in order to meet the needs of their children, were proactive at seeking support from others, were advocates for their children, were active at seeking out information to help them better support their children, and were engaged in learning and acquiring new skills to help them supplement interventions provided by professionals (e.g., speech and language interventions, physiotherapy interventions). Despite the many obstacles they faced, a number of mothers who participated in Study 1 reported feeling confident in their ability to care for their child and meet their child's needs and the results of Study 2 indicated that mean self-report ratings of parents' self-efficacy were high. These mothers reported that the challenges related to having a child with DD helped them grow stronger as people. Further, despite their own challenges, parents reported being able to find peace and gratitude through prayer and made efforts to support other mothers in whatever ways they could. These mothers described the various ways in which they supported one another and relied on one another for inspiration and information alike and many parents reported on the value of upholding this sense of community and mutual support.

One of my goals with this dissertation was to intentionally explore and consider positive outcomes parents might experience as a result of having a child with DD and indeed I found that despite the many challenges reported by parents, they also reported experiencing positive changes in their own lives, and those of their close family and friends. For example, some parents reported that the experience of raising a child with DD made their families stronger and felt that the adversity brought the family closer together. Parents also reported that the experience helped them further cultivate virtues such as patience and love. Additionally, parent ratings of the positive impact of having a child with DD in Study 2, as measured by the Positive Gain Scale (Pit-ten Cate, 2003) indicated that parents in the sample had very high perceived benefits of raising a child with DD.

Despite the overwhelmingly positive perceptions reported by most parents in this dissertation, it is still worth considering ways to continue to promote positive relationships between parents of children with DD and their children. It is possible that parents who were comfortable participating in research about their experience of parenting a child with DD may have been more likely to feel positively towards their children than parents who did not participate in this project. Some research exists on promoting positive perceptions of raising children with DD. For example, in case studies of families in the UK, Dura-Vila and colleagues (2010) describe the important role that cultural or religious beliefs can play in promoting positive attitudes towards children with intellectual disabilities and the perception of the child as a gain and not a loss for the family. Positive attitudes of parents towards their children with DD may also be enhanced through the building of positive relationships. In research with Australian adults with intellectual disabilities and their families, Johnson and colleagues (2012) found that positive relationships were underpinned by processes such as recognising individuality, sharing the moment, connecting, feeling good, and sharing the message. Promoting these ideals and messages amongst Zambian parents can help promote positive relationships between in families who are struggling in this domain.

Conclusion

Overall, this dissertation presents a complex picture of strong and resilient mothers, many of whom face significant barriers to promoting the well-being of themselves or their children, but who remain positive and supportive of one another nonetheless. The results of this project highlight the ways in which parents may be well-supported by some services and advocates in their lives but may find that their support systems fall short in other domains. These parents and their children deserve the same opportunities for success and quality of life that other families in Zambia enjoy. Despite the effort that improving interventions and services for this population will require, promoting positive outcomes in parents of children with DD has the potential to positively impact the lives of the parents themselves, the lives of their children, and Zambian society at large.

This dissertation also provided some directions for future research that may further benefit parents of children with DD. For example, results outlining the experiences of African parents of children with DD can help inform research on African-immigrant parents of children with DD residing in other countries, such as Canada. Research specifically targeting African-immigrant parents is important as parents of children with DD who are also immigrants can face multiple layers of disadvantage (e.g., Khanlou et al., 2015; 2017), and African immigrants are more likely to have children with DD (e.g., Bolton et al., 2014; Dealberto, 2011). Research on the experiences of parents residing in Africa may provide contextual information that can help researchers better understand and address the unique challenges experienced by African-immigrant parents of children with DD, such as discrepancies in healthcare utilization (Pavlish et al., 2010).

Another area for future research, as discussed in Studies 2 and 3, is the need to develop questionnaire measures to assess various factors related to parent stress and outcomes among Zambians, or to establish the validity of using measures developed in other countries with a Zambian sample. The results of Studies 1 and 2 also suggest that future research should examine the complexities of religious coping, and its role in ameliorating challenges for Zambian parents of children with DD, in greater detail. As discussed in Study 3, the relationship between coping and executive functions in Zambian parents of children with DD should be examined in a larger sample. Finally, as discussed above, research on coping skills interventions for Zambian parents is limited. Pursuing such research can help further inform interventions and will support the continued improvement of services for Zambian parents of children with DD.

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Appendix A

Semi-Structured Interview Guide

GENERAL EXPERIENCE (*Do not say these headings out loud to the parents, these are only to guide you in covering the different sections*)

First, I am going to ask you some general questions about your experience so far in raising a child with a disability.

1. How has your journey been so far since your child was diagnosed with ________________.
    a. How old was he/she when he/she was diagnosed?
    b. So, its been_______ years since he/she was diagnosed?
    c. How would you describe your experiences in the past _____ years since his/her diagnosis?
2. Please tell me about what it was like for you when he/she was diagnosed?
3. What was your understanding of __________________'s diagnosis?

    Probe: When did you first notice something was different in your child and what did you notice first?

    Probe: What process did you go through once he/she was diagnosed?

    Probe: What professionals did you go to initially, and since then?
4. Tell me a bit about any challenges that stood out for you during this time.

STRESSORS

Maladaptive & Adaptive Behavior *(If the parent has ALREADY talked about these items,, then DO NOT REPEAT these questions, only ask the questions that you don't yet have an answer for).*

a. Describe some of the stresses that you have experienced over the years.

   b. Did your child have any behavior difficulties?
   c. Tell me about your experience in dealing with his/her behaviors
   d. How independent is your child in daily life skills like personal care, helping at home, interacting with people etc.?
   e. How much do you think your child's skills and behaviours influenced your overall experience in raising him/her
      i. from ***No influence at all*** (1) to ***Extremely influenced*** (10) by it

Other Life Events

1. Did your family experience any big changes or major life events that added to your stress? How did you deal with it?
2. Tell me about some highlights or positive changes you might have experienced as a parent or as a person.

MEDIATORS

Coping

1. Tell me a bit about what helped you cope with the challenges that are related to raising a child with a disability?

   Probe: What kinds of things did you do in order to cope with the challenges you experienced on the way? *(Only if needed)*

2. How did these coping strategies work for you OR how much did you think they influenced your overall experience?
   a. from ***No influence at all*** (1) to ***Extremely influenced*** (10) by it.

Self-efficacy

1. How confident did you feel in your own ability to be able to help your child?
2. Has this changed over time?
3. This confidence in your ability to help your child - how much do you think it contributed to your experience and feelings about it overall?
    a. from ***No influence at all*** (1) to ***Extremely influenced*** *(10).*
    b. Tell me more about it.

Mental Health

1. How have you been feeling yourself? How have your experiences with your child affected you?
2. At different times, did your own state of mind and emotions influence your overall experience?

Family Hardiness

1. In the event of any stressors or challenges, different families can cope in different ways
    a. How do you think your family adjusts and copes?
2. What were some things that you as a family had to adjust with in order to deal with the daily challenges that your experience?
3. Were any of your relationships effected by the time and energy you had to dedicate to your child? How so?
4. To what extent do you think family's togetherness, adaptability and adjustment as a family influence
    a. from ***No influence at all*** (1) to ***Extremely influenced*** *(10).*

Supports

1. What kinds of family supports did you have - from your spouse/partner, his/her family, and friends.

   a. Was it helpful or did it add to your stress at times?
   b. How much do you think it contributed to your experience and feeling.

2. What about more formal services - what kinds of services have you or your child received over the years?
   a. How helpful have you found them to be?
   b. What kind of challenges, if any, did you experience?
3. How much do you think it contributed to your experience?

CULTURAL INFLUENCE

1. In what ways do you think being from Zambia has influenced your experience of raising a child with a disability?

   Probe: Were there ways in which it made things more difficult for you?

   Probe: Were there ways in which it helped you with adapting and coping?
2. What was your family's reaction to your child being diagnosed and the following challenges you faced as a parent?
3. How did other people in your community react to your child's diagnosis? Have you experienced any difficulties socially?
4. Do you think being from Zambia has had a significant influence on any of the different aspects we talked about?

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Appendix B

Parenting Stress in Parents of Children with Developmental Disabilities

Information Letter

Dear Parents,

My Name is **Busi Ncube** and I am a doctoral student in the Clinical Developmental Psychology Program at York University in Toronto, Canada. I am writing to invite you to participate in a research study that I am doing as part of my doctoral dissertation, under the supervision of **Dr. Adrienne Perry**. The study is about the effect of raising a child with special needs such as **Autism, Autism Spectrum Disorder, Pervasive Developmental Disorder, Asperger's Syndrome, Intellectual Disability, Global Developmental Delay, Down Syndrome, Cerebral Palsy, etc.,** on **Zambian** Parents. This letter will describe the study and let you know how you can participate if you choose to do so.

This research has been reviewed and approved by the York University Human Participants Review Committee in Toronto, Canada and ERES Converge IRB in Lusaka, Zambia. If you have any questions about this process, or about your rights as a participant in the study, please contact the secretary of ERES Converge IRB at **[address]**.

What is the Study About?

Other research studies have found that having a child with a developmental disability has a negative impact on parents. As you know, parents experience stress because of the challenges of taking care of a child with special needs. On the other hand, they may also experience some positive results such as more -confidence and stronger family relationships. There are many different factors that can influence the experiences of each parent.

Although most parents experience both challenges and positive results while taking care of their child with special needs, each experience can differ based on their beliefs, how well the child is accepted by the community, how supportive the family and community are, how easy it is to access support services (e.g., through government or community services), and how well the parent understands their child's disability. Therefore, the goal of this study is to see whether these differences have an impact on the experience of raising a child with special needs. We expect that this information will help us to identify ways to help parents cope better and to have a more positive experience with their child. Very little research has been done on this topic, and it is very important to have such research because it could help professionals do a better job of understanding families' needs and responding to them more effectively. This research can also provide guidance to government services and non-governmental organizations about what services and types of support are most needed among parents of children with special needs in Zambia.

What is Involved?

- If you choose to participate, we ask that you complete the questionnaire found in this package. It will take about 45 to 60 minutes to complete.

- You can also choose to complete this questionnaire online.
    - Please go to this link to access the questionnaire **[link to questionnaire]**
- In order to understand your experience more deeply, we will also do interviews with some parents, which would take about 30 minutes on average. If you choose to participate in this interview, we will arrange for a time to meet you in person or talk to you over the phone.
- Your child will not be directly involved in the study.

What are the Potential Risks and Benefits?

To thank you for giving us your time and supporting this research, we will be giving you ZMW 240.

- ☐ If you are completing this questionnaire using the hard copy attached, please fill out the receipt included with this package and return it to Busi Ncube **[phone number]** in the envelope provided.
- ☐ If you are completing this questionnaire online, please fill out your name and address in the space provided at the end of the questionnaire. We will then deliver the honorarium to you.

The questionnaire and interview will involve giving us information about difficult times as well as positive experiences that you have experienced on this journey of taking care of your child. **We do not anticipate any significant risks associated with participating in this study; however, discussing difficult times may bring up sadness, worry, anger, or discomfort. You can choose to not answer any question and you can stop participating in the study at any time if you feel uncomfortable.**

There are many services available to support parents of children with special needs in Zambia. Organizations such as the Zambia Association for Parents of Children with Disabilities and Special Hope Network provide resources for parents of children with developmental disabilities, including financial and emotional support.

Will it be Private?

Yes, we will keep your information private within the limits of law (e.g., if a child is in danger we must notify the proper personnel).

We will only be asking for you name on the consent form, after which you will be given a participant number and your consent form will be kept in a separate file, and only I, Dr. Perry, and the researchers closely involved in this study will have access to it. The actual questionnaire and interview where your answers are written, will only have your participant number.

We will be audio recording interviews in order for us to have time to record and summarize what you say during the interview. We will not say your name on the recording and when we write down what you said in the recording we will do this without including your name. After we have had time to write down what you said during the interview we will delete the recording. **All information will be kept in a locked filing cabinet at York University for 10 years. The office is located in a building that is locked on evenings and weekends. Additionally, digital data, including audio recordings of the interviews, will be stored on an encrypted computer drive. After 10 years, hard copy data will be destroyed by shredding and digital data will be destroyed by deletion and overwriting of drives.** When sharing the results of this study, we will never use your name or identifying you without your written permission.

Do I have a Choice about Participating?

Yes, your participation in this study is completely voluntary and you may choose to stop participating at any time. Your decision not to participate will not affect your relationship with the researchers or York University. You will still receive the same services from any agency that you are involved with.

You can stop participating in the study at any time, for any reason, if you decide to. If you decide to stop participating, you will still be eligible to receive the ZMW 240 for agreeing to be in the project. If you choose to stop participating in the study we will delete or shred all of the data we collected from you immediately.

What is the Next Step if I want to Participate?

If you <u>are</u> willing to participate,

- **please sign the consent form (there is also a copy for you to keep).**
- **If you would also like to participate in the interview, please check off the box on the consent form, and sign the consent form for audio recording.**
- **Please complete the questionnaire and return the questionnaire, consent forms and receipt (if completing a hard copy of this questionnaire) to us in the envelope provided.**

If you have any questions about the study, please contact the researcher, Busi Ncube, at **[phone number] (leave a message for Busi)** or email me at **[email address]**.

Thank you for reading this material and considering this request.

Sincerely,

Busi Ncube, M.A.	Adrienne Perry, Ph.D., C. Psych., BCBA-D
PhD Candidate	Psychologist, Associate Professor,
Clinical Developmental Psychology	York University, Toronto, Canada
York University, Toronto, Canada	

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Parenting Stress in Parents of Children with Developmental Disabilities

Parent Consent Form for Study

I have read and understood the description provided to me about the research being conducted by Busi Ncube and Dr. Adrienne Perry. I understand that the research has been approved by the York University Human Participants Review Committee in Toronto, Canada.

I understand that my participation in the study is completely voluntary and I may choose to stop participating at any time. My decision not to volunteer will not influence the nature of my relationship with York University either now, or in the future. I understand that I will be provided with a ZMW 240 honorarium. If I decide to stop participating, I will still be eligible to receive the honorarium of ZMW 240 for agreeing to be in the project. My decision to stop participating, or to refuse to answer particular questions, will not affect my relationship with the researchers, York University, or any other group associated with this project. In the event that I withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

I understand that all information collected as part of this study will be kept confidential, except as required or allowed by law, and that specific information about myself and my child will only be seen by those directly involved in the research. I also understand that when results are shared in papers or presentations, no information that could identify my family will be used.

I have been provided with the proper information to contact someone if I have any questions about this study.

- ☐ I agree to participate in the study by completing a questionnaire

- ☐ I would also be willing to participate in the individual interview **(Optional. Please read the Consent for Audio Recording Interview, and sign if you agree)**

____________________	____________________	____________________	____________________
Thumb Print	Signature of Parent	Name (please print)	Date

This consent is valid for maximum of one year from the date of signing

☐ I would like to receive a summary of the **results** of the study

Phone number: ____________________________________

or

Email: ____

or

Mail: ____

Appendix C

Parenting Stress in Parents of Children with Developmental Disabilities

Consent for Audio Recording

I have read and understood the description provided to me about the research being conducted by Busi Ncube and Dr. Adrienne Perry. I understand that the research has been approved by the York University Human Participants Review Committee in Toronto, Canada.

I understand that my interview with the researcher will be audio taped for accuracy of interview information. I also understand that:

- This audio taped interview will be transcribed (typed out) without mine or my child's name in it, and my participant ID will be assigned to it.
- This audio tape will be stored separately with the consent form, and nobody excepting the researchers directly involved with the study will have access to the original recording.
- My name will never be associated with any of my responses in the interview, it will never be used in any written papers, presentations or publications, and only a summary of the entire interview data will be presented.

I also understand that I would receive the ZMW 240 honorarium, even if I choose to not to participate in the interview. My decision to withdraw from the interview will not affect my relationship with or any services provided by York University.

I have been provided with the proper information to contact someone if I have any questions about this study.

☐ I agree to being audio taped during the interview, and thus agree to participate in the interview.

In order to set up a time for this interview, please contact me

by phone at __________________ or email at ____.

__________________	__________________	__________________	__________________
Thumb Print	Signature of Parent	Name (please print)	Date

This consent is valid for maximum of one year from the date of signing.

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Appendix D

Parenting Stress in Parents of Children with Developmental Disabilities

Receipt for Honorarium

Please fill out your name and address in the space provided below, so that we can deliver your honorarium (ZMW 240) to you.

By filling this information out, I ___________________________ am giving the researchers involved in this study to mail the honorarium to me. I know I can contact Busi Ncube at [phone number] or [email address] in case I do not receive it or if there are any issues with it.

Address:____

Appendix E

Questionnaire About African Mothers' Experiences In Raising A Child With A Developmental Disability

Please answer these questions about your child with disability, and your experiences in relation to raising this child.

A. Child's gender M F

B. Child's age: __________

C. Child's diagnosis:

- ☐ **Autism / Autism Spectrum Disorders / Asperger's / PDD-NOS**
- ☐ **Developmental disability / Intellectual Disability**
- ☐ **Other____**

D. Was your child born in Canada?

- ☐ **No**
- ☐ **Yes**

E. Which country was your child diagnosed in?

- ☐ **Canada**
- ☐ **Other________________**

F. Please tell us about you as a parent and your family.

F1. How old are you? _______

F2. What is your ethnic background? ____

F3. What language is most frequently spoken in the home?

- ☐ English
- ☐ French
- ☐ Other: _________

F4. Do both parents speak English or French fluently?

- ☐ Yes
- ☐ No

F5. What is the best way to describe the size of your community:

1. Remote area of Canada
2. Rural area of Canada
3. Suburban area of Canada
4. Urban area of Canada

F6. How many adults are living in the household? ________

F7. How many adults, if any, have a disability? ___________

What disabilities (if any)? _________________________________

F8. How many children are living in the household in total, including the child you are reporting about? _________

F9. How many other children (not including the child you are reporting about), if any, have a disability? __________

What disabilities (if any)? _________________________________

F10. What is the birth order of the child you are reporting about?

1. Oldest or only child
2. 2nd oldest child in family
3. 3rd oldest child in family
4. 4th oldest child in family
5. 5th oldest child or later

F11. Please indicate which of the following items you or your family own:

- ☐ Bank account
- ☐ Chair or bench
- ☐ Computer
- ☐ Cupboard
- ☐ Electricity
- ☐ Iron
- ☐ Kitchen
- ☐ Refrigerator
- ☐ Mattress
- ☐ Mobile Phone
- ☐ Radio
- ☐ Sewing Machine
- ☐ Sofa
- ☐ Table
- ☐ TV
- ☐ There are more than 2 people for every room in your home

F12. Please rate your family's access to the following items using the criteria (1 we have this, 2 we would like to have this but cannot it at the moment, 3 we do not want/need this at the moment)

Do you and your family have:

1. A cooked main meal every day?
   - ☐ We have this
   - ☐ We would like to have this, but cannot afford it at the moment
   - ☐ We do not want/need this at the moment
2. Meat or fish every other day?
   - ☐ We have this
   - ☐ We would like to have this, but cannot afford it at the moment
   - ☐ We do not want/need this at the moment
3. A roast meat joint (or something similar) at least once a week?
   - ☐ We have this
   - ☐ We would like to have this, but cannot afford it at the moment
   - ☐ We do not want/need this at the moment
4. Fresh vegetables on most days?
   - ☐ We have this

- ☐ We would like to have this, but cannot afford it at the moment
- ☐ We do not want/need this at the moment

5. Fresh fruit on most days?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
6. Cakes and biscuits on most days?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
7. Good quality ‘brand name’ food for family meals on most days?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
8. A weatherproof coat for each adult?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
9. A weatherproof coat for each child?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
10. Two pairs of all-weather shoes for each adult?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
11. Two pairs of all-weather shoes for each child?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
12. New, not second-hand clothes when you all need them?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
13. A best outfit for the children?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
14. Good quality, new ‘brand name’ clothes or shoes for children?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
15. A celebration with presents for friends and family at special occasions like birthdays?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
16. Toys and sports gear for the children?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
17. Money for trips, holidays, or outings, or going with gifts to parties?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment

- ☐ We do not want/need this at the moment

18. A one-week holiday away from home, not staying with relatives?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
19. A night out once a month?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
20. A colour TV set?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
21. Cable, satellite, or digital TV?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
22. A refrigerator (including a fridge freezer)?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
23. A separate deep freeze?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
24. A washing machine?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
25. A tumble dryer?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
26. A telephone (including a mobile phone)?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
27. A dishwasher?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
28. A video recorder?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
29. Central heating (including storage heaters)?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
30. A microwave oven?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment

31. A car/van?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
32. A music system (tape or CD)?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
33. A home computer?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment
34. Are you and your family able to have friends or relatives for a meal, once a month?
    - ☐ We have this
    - ☐ We would like to have this, but cannot afford it at the moment
    - ☐ We do not want/need this at the moment

F13. Please answer these questions about **yourself**, the person completing the survey:

Marital Status:

1. Married
2. Single (Never married/divorced/widowed)

What is your relationship to the child?

1. Biological parent
2. Adoptive parent
3. Step parent
4. Grandparent
5. Other (Please specify__________________)

Country of birth: ___________________________

If born outside of Canada, how old were you when you moved to Canada?__________________________

How many years have you lived in Canada? _______

What was your reason for moving to Canada?____________________________________

____

What is your first language? ___________________

What is the highest level of education completed?

1. Less than 7th grade
2. Junior high / Middle school (9th grade)
3. Partial high school (10th or 11th grade)
4. High school graduate
5. Partial college (at least one year)
6. College / University graduate
7. Graduate degree

What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver)

____

Do you currently work outside the home?

1. Not currently
2. Part-time
3. Full-time

Have you reduced your work hours to care for the child with a developmental disability?

1. Yes
2. No

Have you increased your work hours to support the family because of having a child with a developmental disability?

1. Yes
2. No
3. Sometimes

F14. **If you have a partner**, please answer these questions

What is his relationship to the child?

1. Biological parent
2. Adoptive parent
3. Step parent
4. Grandparent
5. Other (Please specify__________________)

Country of birth: ___________________________

If born outside of Canada, how old was he when he moved to Canada?_______________________________

How many years has he lived in Canada?

____

What was his reason for moving to Canada?_______________________________________

____

What is his first language? ________________________

What is the highest level of education completed?

1. Less than 7th grade
2. Junior high / Middle school (9th grade)
3. Partial high school (10th or 11th grade)
4. High school graduate
5. Partial college (at least one year)
6. College / University graduate
7. Graduate degree

What is his occupation? Please be specific (e.g., legal secretary, bank executive, truck driver)

____

Does he currently work outside the home?

1. Not currently
2. Part-time
3. Full-time

Has this person reduced his work hours to care for the child with a developmental disability?

1. Yes
2. No

Has this person increased his work hours to support the family because of having a child with a developmental disability?

1. Yes
2. No
3. Sometimes

F15. Have you had to go without any of the following in order to meet your child's needs within the last year? *(Choose all that apply)*

Fresh fruit and vegetables at least once a day
Holiday away from home once a year (not staying with relatives)
Hobby or leisure activity
Shoes or clothing
Small amount of money each week to spend on yourself, not family
New furniture
Car

No

G. Life Events [Items adapted from the Parenting Stress Index – Life Stress Scale (Abidin, 1995) and the GO4KIDDS Survey (Perry & Weiss, 2009)] - During the last **12 months**, have any of the following events occurred in your immediate family?

Has your family experienced (please check all that apply):

Separation
Divorce
Marital reconciliation
Marriage
Pregnancy
Other relative moved into household
Moved to a new location
Promotion at work
Began new job
Trouble with superiors at work
Serious illness or injury
Serious illness of close relative or friend
Recent immigration
Housing problems
Legal problems
Problems with police or other authority
Death of immediate family member
Death of close family friend
Went deeply into debt
Income increased substantially (20% or more)

Has your child with a disability (please check all that apply):

Entered new school
Been suspended or expelled from school
Transitioned to middle school
Transitioned to high school
Transitioned out of high school
Experienced another difficult transition
(Please specify ___________________________)
Had difficulties with teacher
(Please specify ___________________________)
Lost a good Educational Assistant or Teacher
Lost a good paid caregiver (e.g. a nanny, babysitter)
Diagnosis of another child/family member with disability

Income decreased substantially Alcohol or drug problem Serious mental health problems	

H. Child Health – adapted from the GO4KIDDS Scale (Perry & Weiss, 2009)

H1. Compared with other children the same age, how healthy is your child?

1. Very Unhealthy
2. Unhealthy
3. Average
4. Healthy
5. Very Healthy

H2. How often in the past 2 months have you seen the following symptoms in your child? (1 Never, 2 Monthly, 3 Weekly, 4 Daily, 5 Hourly)

	Never	Monthly	Weekly	Daily	Hourly
Anxiety or nervousness	1	2	3	4	5
Depressed mood or extreme sadness	1	2	3	4	5
Obsessive thoughts	1	2	3	4	5
Compulsive behaviours	1	2	3	4	5
Phobic responses or extreme fear	1	2	3	4	5
Psychotic Behaviours	1	2	3	4	5

H3. Does your child have any of the following? (check all that apply)

- ☐ Problems using his/her legs (e.g., walking, running, standing – do not count clumsiness)
- ☐ Problems using his/her hands (e.g., picking things up, holding a pencil)
- ☐ Other problems with motor control/coordination (e.g., very clumsy)
- ☐ Seizures
- ☐ Major vision impairment
- ☐ Major hearing impairment
- ☐ Feeding or eating difficulties (gastro-intestinal problems, feeding tubes, major allergies and sensitivities, etc.)
- ☐ Heart problems
- ☐ Asthma or other respiratory disease
- ☐ Physical dysmorphology (unusual looking face, head, eyes, ears, fingers, toes)
- ☐ Other: ________________________

I. Scales of Independent Behaviour – Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996)

I1. Adaptive Behaviour – Mark how well the individual does (or could do) each task completely without any help or supervision. If you have not seen the individual do the task (or if he or she never has the chance to do the task), mark how well you think he or she could do the task now (without any help). Mark the highest rating (3: Does very well) for tasks that are now too easy for the individual.

	Never or rarely	*Does, but not well*	*Does fairly well*	*Does very well*
1. Makes sounds or gestures to get attention.	*0*	*1*	*2*	*3*

2. Reaches for a person whom he or she wants.	*0*	*1*	*2*	*3*
3. Picks up small objects with hand.	*0*	*1*	*2*	*3*
4. Swallows soft foods.	*0*	*1*	*2*	*3*
5. Transfers small objects from one hand to the other hand.	*0*	*1*	*2*	*3*
6. Stands for at least 5 seconds by holding on to furniture or other objects.	*0*	*1*	*2*	*3*
7. Pulls self into a standing position.	*0*	*1*	*2*	*3*
8. Imitates actions when asked, such as waving or clapping hands.	*0*	*1*	*2*	*3*
9. Puts small objects into containers and takes them out again.	*0*	*1*	*2*	*3*
10. Stands alone and walks for at least 6 feet.	*0*	*1*	*2*	*3*
11. Removes socks.	*0*	*1*	*2*	*3*
12. Shakes head or otherwise indicates “yes” or “no” in response to a simple question such as, “Do you want some milk?”	*0*	*1*	*2*	*3*
13. Points to familiar pictures in a book on request.	*0*	*1*	*2*	*3*
14. Says at least 10 words that can be understood by someone who knows him or her.	*0*	*1*	*2*	*3*
15. Eats solid foods with a spoon with little spilling.	*0*	*1*	*2*	*3*
16. Ask simple questions (for example, “What’s that?”).	*0*	*1*	*2*	*3*
17. Walks up and down stairs by alternating feet from step to step (may hold handrail).	*0*	*1*	*2*	*3*
18. Uses the toilet at regular times when placed on the toilet or a toilet chair or when taken to the bathroom.	*0*	*1*	*2*	*3*
19. Says last name when asked.	*0*	*1*	*2*	*3*
	Never or rarely	*Does, but not well*	*Does fairly well*	*Does very well*
20. Uses the toilet, including removing and replacing clothing, with no more than one accident per month.	*0*	*1*	*2*	*3*
21. Uses complex sentences containing “because” (for example, “I’m not going outside today because it’s raining”).	*0*	*1*	*2*	*3*
22. Takes appropriate-size portions from serving dishes.	*0*	*1*	*2*	*3*

23. Prints first name, copying from an example.	*0*	*1*	*2*	*3*
24. Changes clothing that is dirty from normal wear.	*0*	*1*	*2*	*3*
25. Ties shoelaces and keeps them tied.	*0*	*1*	*2*	*3*
26. Adjusts the water faucets for proper temperature in the bathtub or shower.	*0*	*1*	*2*	*3*
27. Goes at least 4 blocks (or ¼ mile) from home, school, or work alone or with friends of the same age.	*0*	*1*	*2*	*3*
28. Reads and understands materials such as books, comics, or magazines.	*0*	*1*	*2*	*3*
29. Washes and dries dishes and puts them away.	*0*	*1*	*2*	*3*
30. Finds a telephone number in the white pages.	*0*	*1*	*2*	*3*
31. Gives directions to help someone else find his or her way to a place at least ½ mile away.	*0*	*1*	*2*	*3*
32. Accepts criticism of a job without showing anger.	*0*	*1*	*2*	*3*
33. Reads one or more articles in a regular newspaper at least weekly.	*0*	*1*	*2*	*3*
34. Loads and operates a washing machine using an appropriate setting and amount of detergent.	*0*	*1*	*2*	*3*
35. Reaches unfamiliar locations in a city or town with the use of a map.	*0*	*1*	*2*	*3*
36. Makes purchases with a check.	*0*	*1*	*2*	*3*
37. Makes appointments for periodical medical or dental examinations.	*0*	*1*	*2*	*3*
38. Purchases with a credit card, or has loans, and makes payments in a timely manner.	*0*	*1*	*2*	*3*
39. Explains the terms of a written contract, such as installment purchase agreement.	*0*	*1*	*2*	*3*
40. Performs interior and exterior maintenance jobs (for example, painting or replacing broken windows.	*0*	*1*	*2*	*3*

I2. Problem Behaviour – Some behaviours are common at certain ages and are not of concern. Sometimes they cause a problem. If an individual does not exhibit problem behaviours in a category, check “No” and score the item “Never” (0) for frequency and “Not serious” (0) for severity. If you check “Yes,” check its *frequency* and *severity*.

1. **Hurtful to self** – *Does (name) injure his/her own body*—for example, by hitting self, banging head, scratching, cutting or puncturing, biting, rubbing skin, pulling out hair, picking on skin, biting nails, or pinching self?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(circle one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(circle one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

2. **Hurtful to Others –** *Does (name) cause physical pain to other people or to animals*—for example, by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

3. **Destructive to Property –** *Does (name) deliberately break, deface, or destroy things*—for example, by hitting, tearing or cutting, throwing, burning, or marking or scratching things?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

4. **Disruptive Behaviour** – *Does (name) interfere with the activities of others*—for example, by clinging, pestering or teasing, arguing or complaining, picking fights, laughing or crying without reason, interrupting, or yelling or screaming?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

5. **Unusual or Repetitive Habits –** *Does (name) have any unusual behaviours that he/she may do over and over*—for example, pacing, rocking, twirling fingers, sucking hands or objects, twitching (nervous tics), talking to self, grinding teeth, eating dirt or other objects, eating too much or too little, staring at an object or into space, or making odd faces or noises?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

6. **Socially Offensive Behaviour** – *Does (name) behave in ways that are offensive to others*—for example, talking too loudly, swearing or using vulgar language, lying, standing too close or touching others too much, threatening, talking nonsense, spitting at others, picking nose, belching, expelling gas, touching genitals, or urinating in inappropriate places?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

7. **Withdrawal or Inattentive Behaviour–** *Does (name) have difficulty being around others or paying attention*—for example, keeping away from other people, expressing unusual fears, showing little interest in activities, appearing sad or worried, showing little concentration on a task, sleeping too much, or talking negatively about self?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

8. **Uncooperative Behaviour**– *Does (name) have any behaviour that is uncooperative*—for example, refusing to obey, do chores, or follow rules; acting defiantly or pouting; refusing to attend school or go to work; arriving late at school or work; refusing to take turns or share; cheating; stealing; or breaking laws?

No

Yes

a) FREQUENCY: How often does the behaviour usually occur? *(check one)*

0 Never
1 Less than once a month
2 One to 3 times a month
3 One to 6 times a week
4 One to 10 times a day
5 One or more times an hour

b) SEVERITY: How serious is the problem usually caused by this behaviour? *(check one)*

0 Not serious; not a problem
1 Slightly serious; a mild problem
2 Moderately serious; a moderate problem
3 Very serious; a severe problem
4 Extremely serious; a critical problem

J. In the following section, please tell us about the positive and negative impact on YOU as a MOTHER of a child with a disability.

J1. QRS-F – Parent and Family Problems Subscale (Friedrich, Greenberg, & Crinc, 1983). This part of the questionnaire deals with your feelings about your child. There are many blanks below. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False even then. Please begin. Remember to answer all of the questions.

	True	*False*
1. Other members of the family have to do without things because of______.	*T*	*F*
2. Our family agrees on important matters.	*T*	*F*
3. The constant demands for care for _____ limit growth and development of someone else in our family.	*T*	*F*
4. I have given up things i have really wanted to do in order to care for _____.	*T*	*F*
5. _____ is able to fit into the social family group.	*T*	*F*
6. In the future, our family's social life will suffer because of increased responsibilities and financial stress.	*T*	*F*
7. I can go visit with friends whenever I want.	*T*	*F*
8. Taking _____ on vacation spoils the pleasure for the whole family.	*T*	*F*
9. The family does as many things together now as we ever did.	*T*	*F*
10. I get upset with the way my life is going.	*T*	*F*
11. There are many places where we can enjoy ourselves as a family when _____ comes along.	*T*	*F*
12. It is easy for me to relax.	*T*	*F*
13. I get almost too tired to enjoy myself.	*T*	*F*
14. There is a lot of anger and resentment in our family.	*T*	*F*
15. The constant demands to care for _____ limit my growth and development.	*T*	*F*
16. I feel sad when I think of _____.	*T*	*F*
17. Caring for _____ puts a strain on me.	*T*	*F*

18. Members of our family get to do the same kinds of things other families do.	*T*	*F*
19. I rarely feel blue.	*T*	*F*
20. I am worried much of the time.	*T*	*F*

J2Positive Gain Scale (Pit-ten Cate, 2003) - The following statements focus on your own and your family's experiences of having a child with disability.

	Strongly Disagree	*Disagree*	*Not Sure*	*Agree*	*Strongly Agree*
1. Since having this child, I feel I have grown as a person.	*1*	*2*	*3*	*4*	*5*
2. Having this child has helped me to learn new things / skills.	*1*	*2*	*3*	*4*	*5*
3. Raising this child helps put life into perspective.	*1*	*2*	*3*	*4*	*5*
4. Since having this child, my family has become closer to one another.	*1*	*2*	*3*	*4*	*5*
5. Since having this child, my family has become more tolerant and accepting.	*1*	*2*	*3*	*4*	*5*
6. Since having this child, I have become more determined to face up to challenges.	*1*	*2*	*3*	*4*	*5*
7. Since having this child, I have a greater understanding of other people.	*1*	*2*	*3*	*4*	*5*

J3WHOQOL-BREF (World Health Organization, 1997) - The following statements ask how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions**. If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

	Very poor	*Poor*	*Neither poor nor good*	*Good*	*Very good*
1. How would you rate your quality of life?	*1*	*2*	*3*	*4*	*5*

	Very dissatisfied	*Dissatisfied*	*Neither satisfied nor dissatisfied*	*Satisfied*	*Very satisfied*
2. How satisfied are you with your health?	*1*	*2*	*3*	*4*	*5*
	Not at all	*A little*	*A moderate amount*	*Very much*	*An extreme amount*
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	*1*	*2*	*3*	*4*	*5*
4. How much do you need any medical treatment to function in your daily life?	*1*	*2*	*3*	*4*	*5*
5. How much do you enjoy life?	*1*	*2*	*3*	*4*	*5*
6. To what extent do you feel your life to be meaningful?	*1*	*2*	*3*	*4*	*5*
	Not at all	*A little*	*A moderate amount*	*Very much*	*Extremely*
7. How well are you able to concentrate?	*1*	*2*	*3*	*4*	*5*
8. How safe do you feel in your daily life?	*1*	*2*	*3*	*4*	*5*
9. How healthy is your physical environment?	*1*	*2*	*3*	*4*	*5*
	Not at all	*A little*	*Moderately*	*Mostly*	*Completely*
10. Do you have enough energy for everyday life?	*1*	*2*	*3*	*4*	*5*
11. Are you able to accept your bodily appearance?	*1*	*2*	*3*	*4*	*5*
12. Have you enough money to meet your needs?	*1*	*2*	*3*	*4*	*5*

13. How available to you is the information that you need in your day-to-day life?	*1*	*2*	*3*	*4*	*5*
14. To what extent do you have the opportunity for leisure activities?	*1*	*2*	*3*	*4*	*5*
	Very poor	*Poor*	*Neither poor nor good*	*Good*	*Very good*
15. How well are you able to get around?	*1*	*2*	*3*	*4*	*5*
	Very dissatisfied	*Dissatisfied*	*Neither satisfied nor dissatisfied*	*Satisfied*	*Very satisfied*
16. How satisfied are you with your sleep?	*1*	*2*	*3*	*4*	*5*
17. How satisfied are you with your ability to perform your daily living activities?	*1*	*2*	*3*	*4*	*5*
18. How satisfied are you with your capacity for work?	*1*	*2*	*3*	*4*	*5*
19. How satisfied are you with yourself?	*1*	*2*	*3*	*4*	*5*
20. How satisfied are you with your personal relationships?	*1*	*2*	*3*	*4*	*5*
21. How satisfied are you with your sex life?	*1*	*2*	*3*	*4*	*5*
22. How satisfied are you with the support you get from your friends?	*1*	*2*	*3*	*4*	*5*
23. How satisfied are you with the conditions of your living place?	*1*	*2*	*3*	*4*	*5*
24. How satisfied are you with your access to health services?	*1*	*2*	*3*	*4*	*5*
25. How satisfied are you with your transport?	*1*	*2*	*3*	*4*	*5*

	Never	*Seldom*	*Quite often*	*Very often*	*Always*
25. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	*1*	*2*	*3*	*4*	*5*

K. Please tell us about other factors that may impact your experience as a mother.

K1. Kessler 6-Item Psychological Distress Scale (K6; Kessler et al., 2003) - During the **past 4 weeks** how much of the time did YOU feel…

	None of the time	*A little of the time*	*Some of the time*	*Most of the time*	*All of the time*
1. So sad nothing could cheer you up	*0*	*1*	*2*	*3*	*4*
2. Nervous	*0*	*1*	*2*	*3*	*4*
3. Restless or fidgety	*0*	*1*	*2*	*3*	*4*
4. Hopeless	*0*	*1*	*2*	*3*	*4*
5. That everything was an effort	*0*	*1*	*2*	*3*	*4*
6. Worthless	*0*	*1*	*2*	*3*	*4*

K2. COPE Inventory (Carver, Scheier, & Weintraub, 1989) - There are many ways to try to deal with problems. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your problems. Each item says something about a particular way of coping. Please indicate the extent to which you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	Haven't been doing this at all	*Been doing this a little bit*	*Been doing this a medium amount*	*Been doing this a lot*
1. I've been turning to work or other activities to take my mind off things.	*1*	*2*	*3*	*4*
2. I've been concentrating my efforts on doing something about the situation I'm in.	*1*	*2*	*3*	*4*
3. I've been saying to myself "this isn't real."	*1*	*2*	*3*	*4*
4. I've been using alcohol or other drugs to make myself feel better.	*1*	*2*	*3*	*4*

	Haven't been doing this at all	*Been doing this a little bit*	*Been doing this a medium amount*	*Been doing this a lot*
5. I've been getting emotional support from others.	*1*	*2*	*3*	*4*
6. I've been giving up trying to deal with it.	*1*	*2*	*3*	*4*
7. I've been taking action to try to make the situation better.	*1*	*2*	*3*	*4*
8. I've been refusing to believe that it has happened.	*1*	*2*	*3*	*4*
9. I've been saying things to let my unpleasant feelings escape.	*1*	*2*	*3*	*4*
10. I’ve been getting help and advice from other people.	*1*	*2*	*3*	*4*
11. I've been using alcohol or other drugs to help me get through it.	*1*	*2*	*3*	*4*
12. I've been trying to see it in a different light, to make it seem more positive.	*1*	*2*	*3*	*4*
13. I’ve been criticizing myself.	*1*	*2*	*3*	*4*
14. I've been trying to come up with a strategy about what to do.	*1*	*2*	*3*	*4*
15. I've been getting comfort and understanding from someone.	*1*	*2*	*3*	*4*
16. I've been giving up the attempt to cope.	*1*	*2*	*3*	*4*
17. I've been looking for something good in what is happening.	*1*	*2*	*3*	*4*
18. I've been making jokes about it.	*1*	*2*	*3*	*4*
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	*1*	*2*	*3*	*4*
20. I've been accepting the reality of the fact that it has happened.	*1*	*2*	*3*	*4*
21. I've been expressing my negative feelings.	*1*	*2*	*3*	*4*
22. I've been trying to find comfort in my religion or spiritual beliefs.	*1*	*2*	*3*	*4*

23. I’ve been trying to get advice or help from other people about what to do.	*1*	*2*	*3*	*4*
24. I've been learning to live with it.	*1*	*2*	*3*	*4*
	Haven't been doing this at all	*Been doing this a little bit*	*Been doing this a medium amount*	*Been doing this a lot*
25. I've been thinking hard about what steps to take.	*1*	*2*	*3*	*4*
26. I’ve been blaming myself for things that happened.	*1*	*2*	*3*	*4*
27. I've been praying or meditating.	*1*	*2*	*3*	*4*
28. I've been making fun of the situation.	*1*	*2*	*3*	*4*

L. So far you told us about your own experiences. In the following section, please tell us about the experiences of YOUR FAMILY.

L1. The Family Impact of Childhood Disability (Trute & Hiebert-Murphy, 2002) - In your view, what have been the family consequences (positive and/or negative) of having a child with a disability in your family? Please circle answers below.

	Not at all	*To a mild degree*	*To a moderate degree*	*To a substantial degree*
1. We have experienced extraordinary time demands created in looking after the needs of this child.	*1*	*2*	*3*	*4*
2. We have had an unwelcome disruption to "normal" family routines.	*1*	*2*	*3*	*4*
3. The experience has brought us closer to God.	*1*	*2*	*3*	*4*
4. It has led to additional financial costs.	*1*	*2*	*3*	*4*
5. Family members do more for each other than they do for themselves.	*1*	*2*	*3*	*4*
6. Having a disabled child has led to an improved relationship with my spouse.	*1*	*2*	*3*	*4*
7. It has led to limitations in social contacts outside the home.	*1*	*2*	*3*	*4*
8. The experience has made us come to terms with what should be valued in life.	*1*	*2*	*3*	*4*

9. Chronic stress in the family has been a consequence.	*1*	*2*	*3*	*4*
10. This experience has helped me appreciate how every child has a unique personality and special talents.	*1*	*2*	*3*	*4*
11. We have had to postpone or cancel major holidays.	*1*	*2*	*3*	*4*
	Not at all	*To a mild degree*	*To a moderate degree*	*To a substantial degree*
12. Family members have become more tolerant of differences in other people and generally more accepting of physical or mental differences between people.	*1*	*2*	*3*	*4*
13. It has led to a reduction in time we could spend with our friends.	*1*	*2*	*3*	*4*
14. The child's disability has led to positive personal growth, or more strength as a person in mother and/or father.	*1*	*2*	*3*	*4*
15. Because of the situation, we have hesitated to phone friends and acquaintances.	*1*	*2*	*3*	*4*
16. The experience has made family members more aware of other people's needs and struggles which are based on disability.	*1*	*2*	*3*	*4*
17. The situation has led to tension with my spouse.	*1*	*2*	*3*	*4*
18. The experience has taught me that there are many special pleasures from a child with disabilities.		*2*	*3*	*4*
19. Because of the circumstances of the child's disability, there has been a postponement of major purchases.	*1*	*2*	*3*	*4*
20. Raising a disabled child has made life more meaningful for family members.	*1*	*2*	*3*	*4*

L2. Inventory for Family Protective Factors – Compensating Experiences Subscale - How true are the following statements for your family?

	Not True At All	*Mostly Not True*	*Somewhat True*	*Mostly True*	*Very True*
1. Our family has been able to resolve many (but not all) of our problems by ourselves.	*1*	*2*	*3*	*4*	*5*

2. Our family has control over many (but not all) events in our lives.	*1*	*2*	*3*	*4*	*5*
3. Our family has coped well with one or more major stressors in our lives.	*1*	*2*	*3*	*4*	*5*
4. Our family has been able to "make the best out of a bad situation" a number of times.	*1*	*2*	*3*	*4*	*5*

L3. Marital Satisfaction (if married or in long-term relationship) - adapted from the GO4KIDDS Survey (Perry & Weiss, 2009).

Skip these 2 questions if you are single.

I5. How happy is your marriage/relationship?

1	2	3	4	5
Very unhappy	Unhappy	Mixed	Happy	Very happy

I6. How much support do you feel you receive from your spouse/partner related to caring for your child with a developmental disability?

1	2	3	4	5
Makes it more difficult	Not helpful	Somewhat or sometimes helpful	Very helpful	Extremely helpful, I depend on them

L4. Family Support Scale (Dunst, Jenkins, & Trivette, 1984) - Listed below are people and groups that oftentimes are helpful to members of a family raising a child. The following questions asks you to rate how helpful each source is to your family. Please circle the response that describes how helpful the sources have been to your family during the past 3 to 6 months.

How helpful has each of the following been to you in terms of raising your child(ren)	*Not available*	*Not at all helpful*	*Sometimes helpful*	*Generally helpful*	*Very helpful*	*Extremely helpful*
1. My parents	*NA*	*1*	*2*	*3*	*4*	*5*
2. My spouse/partner's parents	*NA*	*1*	*2*	*3*	*4*	*5*
3. My relatives	*NA*	*1*	*2*	*3*	*4*	*5*

4. My spouse/partner's relatives	*NA*	*1*	*2*	*3*	*4*	*5*
5. Spouse or partner	*NA*	*1*	*2*	*3*	*4*	*5*
6. My friends	*NA*	*1*	*2*	*3*	*4*	*5*
7. My spouse/partner's friends	*NA*	*1*	*2*	*3*	*4*	*5*
8. My own children	*NA*	*1*	*2*	*3*	*4*	*5*
9. Other parents	*NA*	*1*	*2*	*3*	*4*	*5*
10. Co-workers	*NA*	*1*	*2*	*3*	*4*	*5*
11. Parent groups	*NA*	*1*	*2*	*3*	*4*	*5*
12. Social groups/clubs	*NA*	*1*	*2*	*3*	*4*	*5*
13. Church or religious community/spiritual leader	*NA*	*1*	*2*	*3*	*4*	*5*
14. My family or child's physician	*NA*	*1*	*2*	*3*	*4*	*5*
15. Child's intervention program	*NA*	*1*	*2*	*3*	*4*	*5*
	Not available	*Not at all helpful*	*Sometimes helpful*	*Generally helpful*	*Very helpful*	*Extremely helpful*
16. School/day-care centre	*NA*	*1*	*2*	*3*	*4*	*5*
17. Professional helpers (social workers, therapists, teachers, etc.)	*NA*	*1*	*2*	*3*	*4*	*5*
18. Professional agencies (public health, social services, mental health, etc.)	*NA*	*1*	*2*	*3*	*4*	*5*
19. Other________________________	*NA*	*1*	*2*	*3*	*4*	*5*
20. Other________________________	*NA*	*1*	*2*	*3*	*4*	*5*

L5. Please add any comments about the positive and/or negative impact of having a child with a developmental/intellectual disability on *you* and *your family*.

L6. Does your child have access to a school that is appropriate for your child and is able to meet your child's needs? ☐ Yes ☐ No ☐ Comment:					
L7. Please rate your satisfaction with the following aspects of your child's schooling on a 5 point Likert scale (1 Very Dissatisfied – 5 Very Satisfied) using the following 11 items					
1. How Satisfied are you with:	1	2	3	4	5
2. Type of classroom and education program	1	2	3	4	5
3. Your child's classroom staff	1	2	3	4	5
4. Communication between you and the school staff	1	2	3	4	5
5. Specialized treatments received in school (e.g., SLP, OT)	1	2	3	4	5
6. Process of setting goals by the school (e.g., IEP)	1	2	3	4	5
7. Your child's academic progress	1	2	3	4	5
8. Your child's behavioural progress	1	2	3	4	5
9. Your child's social skills progress	1	2	3	4	5
10. Your child's inclusion in class activities	1	2	3	4	5
11. Your child's social inclusion by typical peers	1	2	3	4	5
Please add any comments about your child's school situation:					
L8. Medical/Healthcare Support					

1. Do you have a family doctor?
   - ☐ Yes
   - ☐ No
2. In addition to your family doctor do you see any of the following medical specialists to support your child's healthcare needs?
   - ☐ Paediatrician
   - ☐ Developmental Paediatrician
   - ☐ Psychiatrist
3. Do you have a medical specialist who understands your child's disability and is competent in caring for them?
   - ☐ Yes
   - ☐ No
4. Overall, how satisfied are you with the quality of healthcare that your child receives?

Very Dissatisfied	Dissatisfied	Mixed/Unsure	Satisfied	Very Satisfied
1	2	3	4	5

L9. Religious Support

1. Do you have a religious elder or leader who has been able to offer you comfort or other support in response to your child's condition?
   - ☐ Yes
   - ☐ No
   - ☐ Comments:
2. Have you sought support from a traditional healer for your child's condition?
   - ☐ Yes
   - ☐ No
   - ☐ Comments:

L10. Respite Care

1. Do you have any friends or family members who are available to help you take care of your child when you need a break or extra support?
   - ☐ Yes
   - ☐ No
   - ☐ Comment:
2. Do you have access to professional services that will provide you with temporary care for your child (respite care) when you need it?
   - ☐ Yes
   - ☐ No
   - ☐ Comment:
3. If Yes, do you receive this respite care in your home or outside your home?
   - ☐ Inside the home
   - ☐ Outside the home
   - ☐ Both inside and outside the home

M. Stigma

The Stigma-by-Association Scale (Sanden et al., 2015):

People who have children with disabilities at times find that they too are stigmatized by others due to their association with a child who has a disability. This can bring up reactions about what seeking help would mean.

Please use the 5-point scale to rate the degree to which each item describes how you might react in this situation. Circle the number that best corresponds with your opinion.

1 = Strongly Disagree 2 = Disagree 3 = Agree & Disagree Equally 4 = Agree 5 = Strongly Agree

1. There was a time when I worried whether people would find out about my son or daughter's disability.	1	2	3	4	5
2. There was a time when I worried that my neighbours would treat me differently because of my son or daughter's disability.	1	2	3	4	5
3. There was a time when, because of my son or daughter's disability, I felt the need to hide his or her condition.	1	2	3	4	5
4. There was a time when, because of my son or daughter's disability, I kept his or her condition a secret.	1	2	3	4	5
5. There was a time when, because of my son or daughter's disability, I worried that friends and neighbours would avoid me after they found out about it.	1	2	3	4	5
6. There was a time when, because of my son or daughter's disability, I didn't see some of my friends and neighbours as often as I did before.	1	2	3	4	5
7. There was a time when, because of his or her disability, I avoided going to large parties or social events with my son or daughter.	1	2	3	4	5
8. There was a time when, because of my son or daughter's disability, I worried that even my best friends would treat me differently.	1	2	3	4	5
9. There was a time when, because of my son or daughter's disability, I felt ashamed or embarrassed about his or her condition.	1	2	3	4	5

N. Influence of Canadian culture - Please answer each question as carefully as possible by circling *one* of the numbers to the right of each question to indicate your degree of agreement or disagreement.

Many of these questions will refer to your *heritage culture*, meaning the original culture of your family (other than North American), the culture that has influenced you most. It may be the culture of your birth, the culture in which you have been raised, or any culture in your family background. If there are several, pick the one that has influenced you *most* (e.g. Ghanaian, Irish, Chinese, Mexican,). If you do not feel that you have been influenced by any other culture, please name a culture that influenced previous generations of your family.

Please write your *heritage culture* (other than North American) here: ___________________________

Strongly Disagree		Disagree		Neutral/ Depends		Agree		Strongly Agree
1	2	3	4	5	6	7	8	9

1. I often participate in my *heritage* cultural traditions.	1	2	3	4	5	6	7	8	9
2. I often participate in mainstream Canadian cultural traditions.	1	2	3	4	5	6	7	8	9
3. If was/am single, I would be willing to marry a person from my *heritage culture*.	1	2	3	4	5	6	7	8	9

4. If was/am single, I would be willing to marry a typical Canadian person.	1	2	3	4	5	6	7	8	9
5. I enjoy social activities with people from the same *heritage culture* as myself.	1	2	3	4	5	6	7	8	9
6. I enjoy social activities with typical Canadian people.	1	2	3	4	5	6	7	8	9
7. I am comfortable working with people of the same *heritage culture* as myself.	1	2	3	4	5	6	7	8	9
8. I am comfortable working with typical Canadian people.	1	2	3	4	5	6	7	8	9
9. I enjoy entertainment (e.g. movies, music) from my *heritage culture*.	1	2	3	4	5	6	7	8	9
10. I enjoy Canadian entertainment (e.g. movies, music).	1	2	3	4	5	6	7	8	9
11. I often behave in ways that are typical of my *heritage culture*.	1	2	3	4	5	6	7	8	9
12. I often behave in ways that are typically Canadian.	1	2	3	4	5	6	7	8	9
13. It is important for me to maintain or develop the practices of my *heritage culture*.	1	2	3	4	5	6	7	8	9
14. It is important for me to maintain or develop Canadian cultural practices.	1	2	3	4	5	6	7	8	9
15. I believe in the values of my *heritage culture*.	1	2	3	4	5	6	7	8	9
16. I believe in mainstream Canadian values.	1	2	3	4	5	6	7	8	9
17. I enjoy the jokes and humor of my *heritage culture*.	1	2	3	4	5	6	7	8	9
18. I enjoy typical Canadian jokes and humor.	1	2	3	4	5	6	7	8	9
19. I am interested in having friends from my *heritage culture*.	1	2	3	4	5	6	7	8	9
20. I am interested in having Canadian friends.	1	2	3	4	5	6	7	8	9

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Appendix F

Experiences of Zambian Parents of Children with a Disability

Information Letter for Focus Group

My Name is **Busi Ncube** and I am a PhD student in the Clinical Developmental Psychology Program at York University in Toronto, Canada. You recently participated in my study about the experiences of Zambian parents who have a child with a developmental disability. I am inviting a group of [parents/service providers] to participate in a discussion about the study you participated in and the results that we found. We would like [parents/service providers] like yourself to share your opinions on our findings in order to ensure that our interpretations provide an accurate account of your experiences. Please note that you **do not** need to participate in the discussion to get a copy of the results.

Questions About the Research?

If you have any questions about the research in general or about your role in the study, please feel free to contact Dr. Perry by phone at **[phone number]** or Busi Ncube at **[phone number].** You may also email us at **[email address]**. This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, York University, Toronto, Canada.

What is Involved?

- If you choose to participate, we ask that you join us in person for a 1-2 hour group discussion. The discussion will involve us sharing the results of the study with you, and you and a group of other [parents/service providers] letting us know your thoughts and opinions about the results. The discussion may cause you to remember difficult times as well as successes that you may have experienced on this journey of taking care of your child.
- Your child with a developmental disability does not have to attend and will not be directly involved in the study.

What are the Potential Risks and Benefits?

As a token for giving us your time and supporting this research, we will be providing you with an honorarium of ZMW 100 (approx. $12 CAD).

We do not anticipate any significant risks associated with participating in this study; however, discussing difficult times may bring up strong negative emotions and discomfort. You can choose to not respond to certain questions or discontinue participation at any point if you feel uncomfortable.

There are a number of services available to support parents of children with developmental disabilities in Canada. Organizations such as the Zambia Association for Parents of Children with Disabilities and Special Hope Network provide resources for parents of children with developmental disabilities, including financial and emotional support.

Will it be Confidential?

The researchers will make an effort to maintain your privacy throughout the study and afterwards.

We, the researchers, will keep all information you provide confidential within the limits of law (e.g., if a child is in danger we must break confidentiality). ***However, the other research participants will be aware of your identity as you will be participating in the study and sharing information with one another present. We ask that everyone who participates keeps the identity of other participants confidential; however, unfortunately, we cannot guarantee that other research participants will not share your information.***

We will only be asking for you name on the consent form. Your consent form will be kept in a private file, and only I, Dr. Perry, and the researchers closely involved in this study will have access to it.

We will be audio recording focus groups in order for us to have accurate data to summarize. We will transcribe the audio recordings without names and then destroy the audio files. All information will be stored securely in a locked filing cabinet at York University for 10 years. The office is located in a building that is locked on evenings and weekends. Additionally, digital data, including audio recordings of the focus groups, will be stored on an encrypted USB drive. After 10 years, hard copy data will be destroyed by shredding and digital data will be destroyed by deletion and overwriting of drives. When presenting or publishing the results of this research, we will never use your name or identifying information without your written permission.

Do I have a Choice about Participating?

Yes, your participation in this study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future. You will still receive the same services from any agency that you are involved with.

You can stop participating in the study at any time, for any reason, if you so decide. If you decide to stop participating, you will still be eligible to receive the honorarium of ZMW 100 (approx. $12 CAD) for agreeing to be in the project. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible

Thank you for reading this material and considering this request.

Sincerely,

Busi Ncube, M.A.
PhD Candidate
Clinical Developmental Psychology
York University, Toronto, Canada

Adrienne Perry, Ph.D., C. Psych., BCBA-D
Psychologist, Associate Professor,
York University, Toronto, Canada

Experiences of Zambian Parents of Children with a Disability

Consent Form for Focus Group

I have read and understood the description provided to me about the research being conducted by Busi Ncube and Dr. Adrienne Perry. I understand that the research has been approved by the York University Human Participants Review Committee in Toronto, Canada.

I understand that my participation in the study is completely voluntary and I may choose to stop participating at any time. My decision not to volunteer will not influence the nature of my relationship with York University either now, or in the future. I understand that I will be provided with a ZMW 100 honorarium. If I decide to stop participating, I will still be eligible to receive the honorarium of ZMW 100 for agreeing to be in the project. My decision to stop participating, or to refuse to answer particular questions, will not affect my relationship with the researchers, York University, or any other group associated with this project. In the event that I withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

I understand that all information collected as part of this study will be kept confidential by the researchers, except as required or allowed by law, and that specific information about myself and my child will only be seen by those directly involved in the research. **However, I also understand that my identity will be known to the other people participating in the focus group and I am aware that the researchers cannot confirm that the other participants will not share my identity or my information.** I also understand that when results are shared in papers or presentations, no information that could identify my family will be used.

I understand that the focus group will be audio taped for accuracy of collecting focus group information. I also understand that:

- This audio taped focus group will be transcribed (typed out) without mine or my child's name in it.
- This audio tape will be stored separately with the consent form, and nobody excepting the researchers directly involved with the study will have access to the original recording.
- My name will never be associated with any of my responses in the focus group, it will never be used in any written papers, presentations or publications, and only a summary of the entire focus group data will be presented.

I have been provided with the proper information to contact someone if I have any questions about this study.

☐ I agree to being audio taped during the focus group, and thus agree to participate in the focus group.

___________________________	____________________________	___________________
Signature of participant	Name (please print)	Date

This consent is valid for maximum of one year from the date of signing

☐ I would like to receive a summary of the **results** of the study

Email: ____

or

Phone: ____

☐ I give permission for the researchers to share my identity as someone who participated in this research study (NOT REQUIRED).

Appendix G

Focus Group Discussion Guide

Introduction

Hello, my name is Busi as you all know. I'm very appreciative of you joining me here today. The goal of this whole project is to learn about what it is like to be a mother of a child with special needs in Zambia. So I've asked a lot of questions to many mothers and today I just wanted to discuss with you some of the things that I found so I can hear your opinions.

Mutual Respect and Confidentiality

Please when others share their thoughts or opinions it's important for us to be respectful even if we have had a different experience. You can just offer to also share your own experience if it's different from what someone else has said. Also, please don't go and gossip or talk about what other people here have said. It's important that what people say in this group is kept private. We want everyone to be comfortable to share without feeling like someone else here will be telling others what they said. Even us when we share results we won't be sharing your names. We won't go and say "Mrs. So and so said this".

Respect and Encouragement

Please feel free to talk. We won't feel like "this person is talking too much" or "this person is complaining" or "this person is not happy" – no, we want to hear about what you think, that's why we invited you here. So don't answer just "yes" or "no", feel free to elaborate and share your own thoughts.

Focus Group Questions

Many mothers who I talked to said that when you have such a child it is important that you accept the child and accept the child's condition. Now I'm not sure I fully understand what that means. What does it mean to accept it?

Do you think "accepting it" means the same thing to all mothers, or do some mothers mean something else when they say they accepted it?

How is "accepting it" it a positive thing? In what ways does it have a positive impact on your life?

Does "accepting it" mean that you are no longer sad about it?

Does "accepting it" mean that you just wait and see what happens?

Does "accepting it" mean that you just have faith that everything will work out?

Does "accepting it" apply to other challenges in your life? Like if you are having difficulties with a family member would you still use the same method of "accepting it" to cope?

It seems like many marriages end when the child has such a condition.

Is this true?

Why do you think that is?

Do you think it's for the better or do you think it's a problem?

In your opinion what can be done to stop this from continuing to happen?

For couples that stay together, I take it the mother is doing most of the caring for the child. How can fathers help? What do you think mothers need from their husbands in order to have better experiences?

How do mothers need their husbands to support them?

From your husbands do you need financial support, or help with caring for the child, or supportive words or encouragement?

Which do you think is the most important and which is the most lacking?

Most of the women who were married said they were very happy in their marriages.

Do you think that's true that they are happy? Why or why not?

What do you think helps a marriage stay happy when you have a child with such challenges?

How do you think that having money can have an impact on your experience of raising your child?

Do you think that parents have similar challenges with raising children with special needs no matter how much money they have?

It seems as though many mothers who have such children are not able to work. Is this true? Why?

In what ways does having a child with special needs make it difficult to work?

Do mothers wish for jobs only so they can make money or are there other reasons that mothers may want to work (e.g., to meet with friends/coworkers, to follow a passion, etc.)

How do you think schools should be helping such children?

What do you think schools should be teaching these children? Should they be learning to do the same things as other children (e.g., reading, writing)?

Do you think the government schools should be keeping these children in the same classes as other children or do you think they need to be in special classes or special schools?

How do you think doctors or hospitals should be helping parents with such children?

Do you think you need the same care as other parents or do you think you need something special/different from doctors?

What do you think you need from doctors in order to have better experiences?

Some parents have said that it can be difficult when you are seeing a different doctor every time you go to the clinic. Can you tell me a bit more about that?

Some parents have said that doctors do not always have time to give them the information they need to better help their child. Has this been the case for you?

What things does the government do that are helpful for you in terms of raising your child?

What do you wish the government were doing differently?

In what ways can the government be helping more?

Many people talked about support being important. Now there are different ways people can support. People can support by giving money, they can support by helping you take care of your child or run errands, they can support by sharing information with you, or they can support by offering kind words of encouragement. We were not sure which kinds of support are the most important to you.

Which kinds of support do you feel are most lacking?

Many people talked about other people – like family members or even strangers - being ignorant about their child's condition or not understanding such conditions. How does the ignorance of other people affect you in your life?

Do people treat you or your child differently because they don't understand such conditions?

What is this most important thing for other people to know about you or your child's condition?

It seems like many people can have difficulty with their families (e.g., parents, grandparents, aunts, uncles) after they have a child with such a condition, but other parents get a lot of support from their family.

Is this true?

Why do you think some people have such difficulty with their families?

What do you think you need from your families in order to have better experiences?

It seems like some people feel very supported by their friends and neighbours when they have a child with such a condition, while other people have difficulty.

Is this true?

Why do you think some friends and neighbours are so supportive while others are not?

What do you think you need from your friends and neighbours in order to have better experiences?

If you could choose 3 things and say “if only this was different, my life with my child would be so much easier” what would those 3 things be?

What advice would you give to other parents?

What do you wish you had known earlier?

Would it be different if the child did not have such problems?