

Raising Children with a Developmental Disability: Ghanaian-Canadian Parents Shed Insight

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Abstract

Using hermeneutical phenomenology, this study attempts to answer the question: How do Ghanaian-Canadian parents of children with developmental disabilities understand their child's disabilities, and what experiences inform this? By interviewing six Ghanaian-Canadian parents of children with developmental disabilities through semi-structured interviews, it was determined that these parents understood disability broadly. Their understandings were influenced by childhood and post-migration experiences. These experiences were marked by stigma, stress, frustration and joy. Subsequently, the experience of having a child with a developmental disability inspired faith and allowed parents to see their own strengths and abilities in reconceptualizing disability. This research has pointed to broader systemic issues when children are transitioning out of the educational system and the lack of resources to support parents. In spite of strides being made to create awareness, attitudes towards persons with disabilities and their caregivers continues to be a concern for parents. Social workers and the research communities are encouraged to form alliances with minority groups to promote awareness and address barriers that continue to limit these parents and their children's participation in Canadian society.

Chapter 1: Introduction

Disability, including developmental disability, is a concept that connotes numerous meanings. As defined by the Centre for Disease and Control Prevention CDC (2018), a developmental disability is an impairment that may impact a person's physical, language, and learning abilities and behaviors (CDC, 2018). This can range from conditions such as autism spectrum disorder and global developmental delay and intellectual disabilities that may require additional support from family members – more specifically, parents or caregivers. From the moment a parent receives news that their child has been diagnosed with a developmental disability, their lives are altered, and the course of their experiences and understanding are influenced by their child's label of a developmental disability. Disability is an experience that shapes how we see the world and ourselves and those close to us; it cuts across race, gender, class, and sexuality. Such experiences impact the lives of individuals, families, communities and society as a whole. Aside from the definitions, disability has been understood through various models and theories that offer perspectives that help individuals to make sense of their experience.

Most theoretical formulations also provide a Western view of how we perceive disability, which looks at the multiple areas in which persons with disabilities are excluded from society (Bricout, 2004; Buettgen, et al., 2015; Lalvani, 2015). Embedded in our understandings of disability is the notion of stigma which is defined as the negative assumptions and stereotypes associated with the label of disability (Baffoe, 2013; Corrigan et al., 2014; Grue, 2016). In some cases this stigma accompanies how we perceive the label of disability and the experiences that are related to it. The various ways of understanding disability, including stigma, have shaped the lives and experiences of parents. The purpose of this Practice Based Research Paper is to answer

the questions: How do Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability? What experiences inform this? The insight from Ghanaian-Canadians is significant because it can broaden our perspectives on how disabilities are perceived not only through a cultural lens and how factors such as migration may influence people's perceptions and understandings. I wonder what these parents can tell us about their understanding and experiences related to raising a child with a developmental disability. Also, I am hoping to get a sense of parents' subjective experiences and what they can tell us about how disability becomes conceptualized through a cultural lens. I am hoping to learn more about how experiences related to migration may or may not influence our understandings and experiences of disabilities and the ways in which parents resist dominant discourses around disability.

This research is the first to solely examine the experiences and understandings of Ghanaian-Canadian parents of children with developmental disabilities within a Canadian context. However, it bears similarities to the existing research that has been used to describe the experiences of immigrant and black parents of children with developmental disabilities within Western contexts (Munro, 2015; Khanlou, 2017; Greeff & Nolting, 2018; Kinross, 2019). The literature pertaining to my topic has highlighted the extensive work that has been done by the scholarly and research communities; however, most of the literature focuses on homogenizing immigrant experiences, which takes away from their uniqueness. The main focus of the academic community has been to understand access to supports and services (Zechella & Raval, 2016; Marshall & Long; Su, Khanlou, & Mustafa, 2018; Davis, 2018), which only paints a fraction of the picture with limited subjective experiences. In particular, there has been no attention to the experiences of Ghanaian-Canadian parents of children with developmental disabilities.

I became interested in issues around disability early in life and have been passionate about them ever since. My interest eventually led me to academia, where I gained exposure to disability related issues and was fortunate to work with scholars such as Rod Michalko and Geoffrey Reaume, who helped to enrich my knowledge in Critical Disability Studies.

In addition to this, at the age of four, my brother was diagnosed with a developmental disability. I began to reflect on the challenges that my parents experienced raising us and having to access supports to address my brother's needs. As immigrants who had migrated from Ghana, my family were active members of the Ghanaian-Canadian diasporic community, and with my brother's diagnosis, our interactions and participation in community functions and cultural events became limited to non-existent. This impacted not only how I perceived the label of disability; it shaped my parent's experiences as well.

The study holds significance in the field of social work for several reasons. First, it bridges the gap in literature that has yet to address the experiences of Ghanaian-Canadian parents of children with developmental disabilities within a Canadian context. Second, this project will help to create awareness on the complexities of disability in Ghanaian-Canadian communities. Thirdly, this research will help to demystify disability and parenting within these communities. It is my hope that through this research, and through the shared experiences of these parents, integration can be encouraged. Lastly, academia and the field of social work can gain invaluable knowledge from these parents' experiences that will shape intervention practices and how we understand disability through a cultural lens that speaks to Ghanaian-Canadian parents' interpretations.

Organization of This Study

This research project is divided into five chapters. Chapter 1 has introduced my topic by providing a brief overview of the understandings and experiences of Ghanaian-Canadian parents of children with developmental disabilities. My interests and significance of this research in the field of social work and academia. Chapter 2 outlines the literature assessment that will include identifying key studies while exploring concepts such as disability, race, stigma and themes related to social support, mourning and acceptance. The chapter identifies methodological trends and gaps in other studies that have explored the experiences of parents raising children with developmental disabilities. It also highlights methods used to approach this topic and makes an argument for hermeneutical phenomenology.

Chapter 3 lays out the plan that I used to approach my research. I discuss the paradigm and methodology. In this section I also describe the research design, inclusion criteria, sample size, recruitment strategies, data collection, data storage and analysis, in addition to ethical issues related to risk, harm and confidentiality. Chapter 4 addresses findings and discussions. Along with this, findings will be read against the literature assessment to highlight some of the similarities and distinctions to other studies that have been conducted. The research question will be answered in this section under major themes and subthemes. Chapter 5 provides a summary, reflection, recommendations and limitations of this study.

Chapter 2: Literature Review

A plethora of research describes the experiences of immigrant mothers of children with developmental disabilities within a Canadian context. One common agreement shared between scholars and researchers that focused on Ghanaian or Canadian contexts is that social stigma is a

pressing concern that influenced their experiences and understandings (Khanlou, 2017; Munroe, 2015; Baffoe, 2013; Oti-Boadi, 2017). One area of contention was the social supports, while some parents felt supported by service providers, a majority of the research pointed to the lack of culturally appropriate supports. One influential scholar in this field of research is Nazilla Khanlou. In 2018, she explored the experiences of immigrant mothers of children with developmental disabilities in accessing social supports (Khanlou, 2018). In addition to this, Khanlou et al. (2017) discussed the barriers associated with immigrant mothers accessing supports for their children with developmental disabilities (Khanlou, 2017). She has been pivotal within the literature describing such experiences and found that immigrant mothers lack social supports in Canada.

For parents of children with physical disabilities, Depape & Lindsay (2015) find that people with physical disabilities are less likely to experience stigma as opposed to those with developmental disabilities because these children appear “normal” (Depape & Lindsay, 2015). Three researchers made mention of African-American parents experiences of having children with a developmental disability and three researchers focused specifically on their experiences in the Africans living in western countries such as the United States and Europe. The common theme in the research was a discussion on how spirituality influenced perceptions of disability. For example, Ha et al. (2011) who examine the experiences of African-American parents raising children and the impacts on their physical and mental health (Ha et al., 2011). Also, Avoke (2002) is foundational and other Ghanaian scholars and researcher’s reference him when talking about spiritualities that shape parents’ experiences of having children with developmental disabilities in a Ghanaian context (Avoke, 2002). Both Oti-Boadi (2017) and Badu (2016) draw on Avoke’s conceptualization to capture the lived experiences of Ghanaian parents of children

with developmental disabilities (Oti-Boadi, 2017). However, there has been no research that explores how Ghanaian-Canadian parents of children with developmental disabilities make sense of their child's disability and the experiences that inform this.

Three studies focused on the experiences of African parents in Western societies and how they make sense of their child's disability. Munroe (2015) comes close, as she seeks to review literature about the experiences of South Asian and African immigrants living in Western societies. She finds that there is a "clear need for the experiences of African parents to be individually explored". Parents pointed out the negative experiences that they had with service providers, coupled with lack of awareness and barriers related to language and cultural beliefs (Munroe, 2015 p.52). This points to a gap in the literature and solidifies the need to investigate the individual experiences and understandings of Ghanaian-Canadian parents of children with developmental disabilities.

Especially relevant for this research is literature that focused on the experiences of parents as well as their understandings. The strength in most of these studies that I found was that they spoke to the immigrant experience within western societies like Canada, the United States and Europe. Other studies made a distinction between the experiences of mothers and fathers raising children with disabilities. In addition, the rest of the literature focused more generally on the experiences of parents of children with developmental disabilities.

The Concept of Disability

Disability is a concept that has different meanings for different people and as such, needs to be clarified within the context of this research. The Ontario Human Rights Commission (OHRC) defines disability as:

Any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness ... [anyone using a] wheelchair or other remedial appliance or device; a condition of mental impairment or a developmental disability. (OHRC, 2018)

This definition views disabilities in terms of impairments that can be both visible and invisible, that requires additional support. A developmental disability becomes an impairment that may impact a person's physical, language, learning abilities and behaviors (CDC, 2018). This can range from intellectual disabilities, autism, and learning disabilities which will be used interchangeably throughout this research. Ray (2018) argues that almost everyone will experience disability at some point in their lives. Disability then becomes a natural phenomenon that most of us experience whether it is from birth, or through injury or aging. The World Health Organization (WHO) (2011) draws on the International Classifications of Functioning (ICF) Disability and Health that solicits the interpretations of persons with disabilities, scholars, educators and service providers to develop a bio-psycho-social model. This model places emphasis on the disability, how it impacts the individual's ability to perform daily tasks and the experiences that arise from having a disability such as discrimination, employment limitations, etc. (WHO, 2011). The identity of parents is not mentioned, leaving readers to draw their own conclusions. Experiences of gender, race and cultural discrimination can influence how we interpret disability, and yet parents, who have a major impact on how their child's disability is interpreted, are obscured. Bricout (2004) notes that the first point of contact for parents whose child receives a diagnosis of a developmental disability is the medical field. Parents come to understand their child or children's disability through a medical model that views a developmental disability in terms of a physiological problem in need of fixing and as such, interventions are focused on the impairment, rather than other factors (Sloper, 1998).

These understandings are extended to the individual model that views disability as located within the individual, reinforcing the idea that disability is a personal and unfortunate tragedy and evokes feelings of pity (Oliver, 1990). In addition to pity, such understandings promote blame and offloading on parents as they are left to be the only sources of support for their children. In contrast, by developing the social model of disability, theorists and activists have challenged the medical views noting that it is society that disables people with developmental disabilities through exclusionary practices and the built environments (Shakespeare, 2006). This view alludes to oppression; however, it is vague and does not speak directly to how culture may inform parents' understandings. The lack of focus on internal factors leads to parents' understanding their child's disability in terms of impairments, which neglect parents' experiences and conceptualizations of a child's disability.

Nonetheless, within the context of Ghanaian culture, disability can be known through a religious model that asserts that disability is a punishment handed down by a supernatural being to children for the sin of their parents and/or families and extended family members (Avoke, 2002; Abang, 1988; Oti-Boadi, 2017; Badu, 2016). Alternatively, being a parent of a child with a disability can be perceived as a blessing and God's will, being manifested in the lives of these families. Caring for these children becomes shared between parents and is a broader societal responsibility (Abang, 1988).

In the theoretical orientations that seek to conceptualize disability, critical disability theory focuses on the social, cultural, political and economic factors that lead to the exclusion and denial of rights and access for persons with disability and their caregivers (Buettgen, et al, 2015; Lalvani, 2015; Baffoe, 2013). Since this theory is steeped in Western and Eurocentric thought, there is a danger that such theories can subjugate Ghanaian ways of knowing, such as

the religious understandings highlighted above. Hence, an inductive approach in my research will be useful, as it allows me to honour Ghanaian-Canadian epistemologies.

In my research, I want to study the way these conflicting worldviews affect the lived experiences of parents and their children with developmental disabilities. These definitions and models highlight the tensions between Western and Ghanaian conceptualizations of disability.

The Concept of Race

Given that this research project focuses on minority groups living in western societies, it is assumed that issues of race will emerge. Race is a socially constructed term that refers to the colour of an individual's skin, and shapes the understanding and experiences of a particular phenomenon. For example, Gillborn (2015) states that “whiteness is a racial discourse that refers to a set of assumptions, beliefs, and practices that place the interests and perspectives of white people at the center of everyday life” (Gillborn, 2015, p. 279). Thus, whiteness represents a privileged identity and epistemology, whereas other minority groups that do not fit into the mold of whiteness are rendered as the other and their ways of knowing and being are devalued. Fanon (1970) and Bailey (2018) state that blackness is associated with a ‘moral dirtiness’, the ‘savage who is unrefined’, and represents ‘death’ and a threat to whiteness. The binaries of black and white set the tone for race relations in Canada, where Ghanaian-Canadian parents reside.

However, viewing the experiences of parents through the binaries of race works to maintain the ideologies of us and them and does little to provide a deeper meaning outside the scope of race.

hooks (1992) juxtaposes these racial binaries by saying that it is not just about the belief that one race is more superior than another race; rather, the concern is about our positionality, which goes beyond unsettling the status quo (hooks, 1992). However, our positionality changes,

evolves and digresses with experiences of migration and acclimatization, while other identities become visible, such as the birth of a child with a developmental disability. These subjectivities influence how we understand developmental disabilities and the experience that informs this. For example, in Dávila's (2015) study that sought to observe the experiences of racialized students with disabilities and how they responded to racial microaggression, her findings were obscured by the presence of disability microaggression in the subtle, direct and indirect comments made by staff and fellow students. The experiences of these parents are embedded with notions of race, gender, disability and class, that unsettle understandings of disability. Although this complicates matters of disability, it assumes that these are the only experiences, As Lorde (1984) puts it: "There is no such thing as a single issue-struggle because we do not live single issue lives" (Lorde, 1984 p.). Thus, the experiences of raising a child with a developmental disability are not limited to experiences of disability; this set of experiences is complicated by sexuality, gender, childhood memories and circumstances, race, class and so on.

Several theorists and activists with vested interests in the issues of race and racism have developed frameworks from which we can conceptualize black parents' understandings and experiences. Critical race theorists and activists argue that since racism is an everyday experience in the lives of black people, race should be a focal point as it intersects with other identity markers (Gillborn, 2015, p. 279; Bailey, 2018; Fanon, 1970; Davila, 2015; Delgado & Stefancic, 2001). The framework does little to address experiences where gender, sexuality or disability take precedence over race, or instances where the double identity of Ghanaian and Canadian are in tension with one another. W. E.B. Du Bois (2007) eloquently captures the dual identity of being Ghanaian and Canadian by saying:

double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. One ever feels his two-ness,—an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder. (Du Bois, 2007, p. xiii)

This twoness reveals how minority groups are perceived in western contexts and the emotional struggles to reconcile these dual identities. A double consciousness, albeit, useful, limits the challenges of parents of children with developmental disabilities to public perceptions and conflicting cultural beliefs and values, coupled with the emotional tensions. This does not account for values and beliefs around gender, class, and sexuality and how these can complicate one another.

Other Black feminist scholars have taken this notion of double consciousness and expanded it to create an intersectional framework. An intersectional framework examines how concerns related to race, gender, sexuality, class, disability and ethnicity play out in various settings to create multiple interlocking oppressions (Crenshaw, 1991; Gillborn, 2015; Bailey, 2018). As Lorde poignantly puts it, “There is no such thing as a single issue-struggle because we do not live single issue lives” (Lorde, 1984, in Bailey, 2018, p. 20-21). Thus, the experience of raising a child with a developmental disability is not isolated to the experiences of disability; rather, there are multiple intersecting factors related to parenting, integration into western societies, gender, race and class that will help to reveal meanings ascribed to disabilities. Ghanaian-Canadian parents of children with developmental disabilities possess multiple identities, and intersectionality will help to reveal the essence of their understandings and experiences.

The Concept of Stigma

The work of Irving Goffman helps to conceptualize stigma, which came up in the numerous studies exploring parents' experiences. Stigma can be defined as the negative attitudes and stereotypes that are held towards people with disabilities Grue (2016) notes that disability is a label that signifies a bodily difference (Grue, 2016). These labels are embedded with assumptions and stereotypes about groups of people on the basis of differences such as disability, race, immigrant status, gender, sexuality and so on. Corrigan et al. (2014) identify three types of stigma: self, public and structural. Self-stigma implies the negative feelings of shame and rejection that are generated from these labels that one believes to be true about the self.

Social stigma refers to the attitudes and assumptions that the general public holds as true about people's differences. The institutional policies and practices that reinforce these assumptions represent structural stigma (Corrigan et al., 2014). Stigma was identified in the literature pertaining to the understandings and experiences of raising children with developmental disabilities (Corrigan et al., 2014). Social stigma was a concern that parents expressed, as it limited participation and influenced their experiences (Khanlou, 2018; Badu, 2016; Oti-Boadi, 2017). Social stigma was identified as a key concern that limited parents' participation in their communities, either as a result of discrimination and stereotypes faced by potential employers or the stigma associated with other markers of their identity, such as race or immigration status (Badu, 2016; Khanlou, et al., 2014).

For other scholars and researchers, traditional and cultural stigma influenced the experiences and understandings of parents raising a child with an intellectual disability. Perhaps the challenge of raising a child with a disability is not necessarily due to the behaviours or severity that accompanied the disability, it is as a result of social stereotypes, rejection and

exclusion (Khanlou et al, 2018; Woodgate, 2008; Kinnear, 2015). Davis (2018) finds that stigma prevented parents from seeking supports from service providers or community members (Davis, 2018). In contrast, Khanlou et al., (2017) argues that it is rather the stigma that they experienced from family and friends that caused parents not to seek outside support (Khanlou et al., 2017). Some Ghanaian parents were concerned that the stigma associated with having a child with a disability would negatively impact their other children's chances at marriage (Hervie, 2013). Avoke (2002) argues that in Ghana, once a child is labelled as having a disability, they are placed in specialized schools, which automatically stigmatizes the children who attend that school (Avoke, 2002). Oti-Boadi (2017) suggests that the best way to deal with this issue is to create awareness by facilitating anti-stigma campaigns to educate the public on the cause and experiences of parents of children with developmental disabilities (Oti-Boadi, 2017). Since Hervie (2013), Avoke (2002), and Oti-Boadi (2017) agree that stigma is a powerful force in making parenting challenging for Ghanaian parents of children with developmental disabilities, my research will aim to understand how stigma functions among Ghanaian-Canadian parents and how stigma might change in Western contexts.

Methodological Trends and Gaps

There have been multiple methods employed to address the experiences of parents of children with developmental disabilities. The following section illustrates the various approaches used and identifies the gaps in the existing literature. Khanlou, et al., (2015)'s *descriptive study* on immigrant mothers of children with disabilities, parents found it challenging to understand their child's disability because they were not familiar with medical terminology used in reference to their child's disability. Navigating systems of supports presented more stress for the parents

(Khanlou, et al, 2015). There are three areas of concern with this study. The most evident is that service providers' knowledge is valued over that of parents. Second, to purely describe parents' experiences takes away from parents' interpretations of their own experiences and understandings. Third, capturing only mothers' experiences neglects fathers, trans people, queer people, same-sex couples, married and single parents of children with disabilities whose experiences will be distinct. A strength in this research is that it captures some of the immigrant experience in accessing supports through a qualitative approach that can be potentially useful in this study.

In contrast to this, Depape & Lindsay's (2015) qualitative study uses *focus groups* to solicit the responses of parents on their understandings of their child's disability. Most parents were coming from diverse backgrounds including Canada. They used a *metasynthesis* to analyze their data and found that the experiences of being married and caring for a child with a disability had a positive impact on their relationship. The other parents felt that it created more strain on their relationships and in some cases led to divorce (Depape & Lindsay, 2015). Although this method of analysis draws on aspects of phenomenology, such research has been used to benefit medical field that promotes positivistic thinking (Lachal et al., 2017). However, the focus group setting cannot maintain confidentiality or anonymity, and within such groups, participants may be reluctant to engage because of personal boundaries, limits and fears.

The stigma that is associated with disability makes it challenging at times for parents to speak openly and publicly about their lived experiences and understandings of their child's disability. Essentially, this is why I have chosen to conduct one-on-one interviews in intimate settings with participants, as it will allow for flexibility and encourage a genuine openness that will generate rich descriptive data.

Burrell, et al., (2017) use an interpretative phenomenological analysis to capture the experiences of white British fathers in the United Kingdom of children with developmental disabilities who are currently underrepresented in the research within this area (Burrell, et al, 2017). One of the fathers states, “some of the things that would irritate you when you don’t understand...once you understood that wasn’t him being...rude or obnoxious...it’s just [your son]. And then that took a lot of pressure off” (Burrell, et al., 2017 p. 1139). Using a phenomenological framework proves to be beneficial because it helps the research to capture reflections and interpretation from first-hand accounts of these fathers (Burrell, et al., 2017). In this example, understanding came with separating the behaviours associated with the disability from the person. It is my hope that through this research I will be able to capture, gender, race, space, culture and migration experiences and how they can have a profound effect on the understanding and experience of parenting a child with a disability, which has not demonstrated in this research.

Three important issues remain unexplored in the literature: first, the experiences of black same-sex parents raising children with developmental disabilities within a Canadian context: second, the experience of trans, queer, and/or non-binary parents of children with disabilities both within a Ghanaian and Canadian context: third, there has been minimal research on the experiences of fathers, more specifically black fathers. Such limitations reinforce patriarchal and racist assumptions that mothers are the only ones involved in caregiving roles. This points to a gap in the literature and an area that needs to be explored in future research.

Social Support

There has been extensive research identifying social support as instrumental in determining how parents perceived their child's disability and the experiences that inform them (Khanlou et. Al, 2018; Griffith, 2012; Ferguson, 2002; John et. Al, 2015). Using qualitative approaches, parents from diverse backgrounds of children with disabilities defined support as the amount of aid one receives, whether it be information, financial, emotional supports from friends, family members, communities or service providers, which can be helpful to parents and their children (Su, Khanlou & Mustafa, 2018; Jennings et al., 2014; John & McCullough, 2016). Other parents emphasized the importance of support from doctors, school officials and psychologists in understanding their child or children's disability (Greeff & Nolting, 2018; Davis, 2018). Despite the feelings of isolation, some parents showed resiliency in spite of limited supports from families, communities and service providers.

Ferguson (2002) frames social support as being the set of internal and external resources parents had in response to a child's disability (Ferguson, 2002). For the parents in the study Griffith, et al. (2012), having internal strength meant that the only supports that were needed were the emotional and practical ones that they provided for their children to ensure their wellbeing (Griffith, 2012). In contrast to this view, the parents interviewed by John et al. (2015) understood social and emotional support for immigrant parents as fundamental to the stressors associated with raising a child with a developmental disability. The socio-emotional support that parents and their children received from service providers, community members and spouses contributed to a positive perception of a child's disability and fostered a sense of inclusion (John et. al, 2015). The absence of support increased stress among parents, which in turn, influenced how parents interpreted their children's disability. For some parents the support that they

provided for their children often went unnoticed, which led to feelings of isolation (John et. al, 2015).

Several researchers have noted that there is a lack of these supports for parents of children with developmental disabilities who have immigrated (Aguerre et. al, 2018; John et. al, 2016; Marshall and Long, 2010). Most notably, Jennings et al. (2014) and Khanlou (2017) argue that immigrant mothers living in Canada received little to no support, partly due to migration and settlement challenges coupled with lack of quality supports to address their unique needs (Jennings, et al., 2014). This led to increased stress for single parents and challenges coping (Ha, et al., 2011). In contrast, other mothers felt supported by service providers and their communities and spoke about the close relationship with these providers (Marshall & Long, 2010 p.114). For Indian immigrants of children with developmental disabilities living in the states, support received from spouses was foundational in shaping their perceptions of their child's disability (John et. al, 2015).

Similarly, in their qualitative analysis, Asian Indian parents in Zechella & Raval's (2016) study experiences argued that spousal support while raising children with intellectual and developmental disabilities strengthened marital bonds (Zechella & Raval, 2016). In stark contrast to this, Badu's (2016) exploratory study of mothers' experiences in Ghana was striking. One participant recalls, "My husband also left me with my three children upon the realization of an intellectually disabled child" (Badu, 2016, p.24). Other Ghanaian parents reported that the emotional and practical support that they received from friends, church members and spouses created positive perception of having a child with a disability (Oti-Boadi, 2017).

For the mothers quoted in Bunner's (2011) dissertation, parents felt that social supports came from other parents who had children with developmental disabilities (Bunner, 2011).

Likewise, the mothers in John et. al, (2015) study found that parent support groups were helpful in determining positive interpretations of their children's disability (John et. al, 2015). Fathers echoed similar sentiments, as they described the assistance from service providers as heterogeneous, and lacking a "personal feel" (Burrell et al., 2017 p.1142).

Researchers have reported that parents felt that stereotypes by service providers, friends, family, and community members prevented them from receiving the supports that they need (Nurullah, 2013; Altieri & Von Kluge, 2009; Burrell, 2017; Greeff and Nolting, 2018). In order to address the concerns around the lack of support that some parents reported, the focus should be geared toward promoting public acceptance and understanding of persons with disabilities as a way to challenge the assumptions towards parents and their children (Baffoe, 2013). Depape & Lindsay (2015) add to this by stating, "It is important that health care professionals work to increase public awareness about [developmental disabilities] and provide support to parents to help them actively participate in their communities" (Depape & Lindsay, 2015 p.579). Other researchers argued that the supports that parents seek out in making sense of their child's disability is influenced by their culture and therefore, supports needed to be culturally sensitive (Ennis-Cole et al., 2013; Heer et al., 2015; John et. Al, 2015; Oti-Boadi, 2017). In spite of the various perceptions of social supports, the literature pointed to challenges in coming to terms with a child's diagnosis. Given how distinct parents thinking about social support, I may probe Ghanaian-Canadian parents about the supports they have accessed and the support services and the reasons why they may or may not access them.

Acceptance and Mourning

A prominent feature of the literature in parents' understanding of their child's disability was acceptance and mourning, which helped them come to terms with their child's diagnosis. Acceptance was described by parents as being a lifelong journey that began with their child's diagnosis that came with feelings of frustration, shame and embarrassment (Burrell, et al., 2017). This meant learning to cope with negative attitudes and society perceptions of a child's disability (Sloper, 1996; Badu, 2016). For other parents, this meant looking forward to the future, embracing the child's disability as the "new normal" (Burrell, et al, 2017). In contrast to this, the mothers in Bunner's (2006) dissertation, news of their child's disability was a stressful time. As one mother states,

You know our 14-year-old is starting to figure out that he's different. He doesn't want to admit it, he doesn't want to accept it, you know, his years ahead are going to be hard. That stresses me out if I think about it... It does because, because you see it coming, so you know how they're gonna be hurt. (Bunner, 2006, p. 82)

In stark contrast to this, Greeff & Nolting (2013) found a positive relationship between parents' acceptance and their outlook which created optimism about the new challenges that they experience as they looked forward to new experiences.

This process of acceptance was difficult for all members of the family, including siblings. Ennis-Cole et. al (2013) argue that culture not only influences how parents perceive a child's diagnosis, but also influences how they come to accept their disability. Both Badu (2016) and Khanlou (2017) complicate this further by arguing that in some communities that are steeped in traditions that uphold the "normal" child, some children and their caregivers are not acknowledged because it is culturally unacceptable to have a child with a disability. Agbenyega (2003) and Avoke (2002) argue that the label of disability is so powerful that it becomes a

determining factor as to what is acceptable or unacceptable. Persons with disabilities come to accept the stigma associated with their identity as being essentially part of who they are.

However, parents described having difficulty accepting their child's disability. One parent noted, "It's a grief, you know. Everyone offers you, do this, do that, go to that practitioner" (Zechella & Raval, 2016). Mourning the loss of an expected 'normal' child when it turns out that their child has an unexpected disability signified this parents' hopes of having a "normal" child and when it appeared not to be the case, this parent grieved. Other parents preferred not to spend time mourning but instead appreciate the children that they have.

In the examination of narratives that parents posted on the internet, Fleischmann (2004) captures the positive outlooks with one parent stating, "If you spend your life mourning the fact that you didn't get to [have a normal child], you may never be free to enjoy the very special, the very lovely things about [a child with a disability]" (p. 40). Although parents shared differing perspectives on having a child with a disability, one thing that is evident is the perception of normalcy, which was indicated by the presence of a child with a developmental disability. Once parents had come to terms with their child's diagnosis, they often spoke about benefits that came along with parenting a child with a disability. Some parents noticed that they became more patient, more accepting of differences and better able to cope as they drew their strengths from their children (Depape & Lindsay, 2015; Kayfitz, 2010). For persons with disabilities, acceptance was not an issue as they could not imagine their lives without a developmental disability (Depape, 2016). What I continue to wonder while conducting the literature review is how Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability which has yet to be answered.

From the literature assessment exploring the various ways of knowing, disability can be known through concepts such as labeling and stigma that speak to the individual, social and structural domains that shape people's experiences. Many definitions provided by the frame disability in terms of impairment or list the expert opinions of scholars, researcher among others, excluding parents experiences. The medical, individual and have attempted to fix disability or pit the problem on the individual, where as the social model focuses on the external factors that disable parents of children with developmental disabilities. As helpful as Critical Disability Theory may have been, it limits Ghanaian parents ways of knowing which in many cases is guided by a religious worldview from the research that has been conducted thus far (Oti-Boadi, 2017; Avoke, 2002, Baffoe, 2013; Badu, 2016).

The concerns elicited in the literature support the importance of using an inductive approach. As outlined in the literature, several scholars and researchers have simply described parents experiences without a reflection of their understanding. This is the reason why I have chosen hermenutical phenomenology as it allows for both descriptions and interpretations of parents experiences. The use of a focus group in conducting research on this topic can be impersonal and may create more barriers. Research that used strains of phenomenology captured the experiences of fathers, while other spoke to the fact that my topic is an area that needs to be researched. A common theme within the literature was social suport which parents have differring views on, it would be interesting to see the insight that Ghanaian-Canadian parents share through this research. Acceptance and mourning were also common themes as most parents had difficulties coming to terms with their child's disability and in some cases parents mourned the 'normal' child. For those parents who were able to come to terms with their child's disability, it became a source of strength.

Through the use of hermeneutical phenomenology, I intend to capture the subjective experiences of Ghanaian-Canadian parents of children with developmental disabilities using semi-structured interviews. I endeavour to integrate different ways of conceptualizing disability through the experiences of Ghanaian-Canadian parents and thus, introducing such orientations within the field of social work.

Chapter 3: Design and Methods

This chapter focuses on the design and methods that I used to conduct this research. I describe the paradigm, sample size, inclusion criteria, recruitment methods, data collection and analysis and any ethical issues I anticipated during this research. I also discuss data storage and dissemination that was employed throughout this research.

Paradigm

The aim of this research was to answer the research questions: How do Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability? What experiences influence this? The research used a qualitative approach that allowed me to capture the multiple interpretations and how meanings become constructed and evolve over time and space (Good-Gingrich, handout, 2018). As such, hermeneutical phenomenology compliments this paradigm, as it aims to understand the essence of shared experiences of a particular phenomenon (Adam & Manen, 2008; Kafle, 2011; Anderson-Nathe, 2008). The theoretical approach will allow my research to see how parents make sense of their understanding and how they have come to perceive disability. The decision to use this

methodology was further strengthened by the diverse approaches that I assessed in the literature which highlighted the need to examine this topic using hermeneutical phenomenology.

In the literature review, I examine a few studies that use strains of phenomenology, which led me to selecting hermeneutical phenomenology for this study. For example, Bunner (2011) notes “phenomenology provides for a more in-depth description and interpretation of raw data (texts or personal narratives without becoming overly focused on the scope or application” (Bunner, 2011. p. 52). The focus is not on following a set of prescriptive measures but collecting rich data that reveal deeper meanings of parents’ understandings and experiences. Burell et al. (2017) capture this in their use of hermeneutical phenomenology that describes and interprets the underlying meanings that are ascribed to parenting a child with a disability (Woodgate, 2008). The strength of hermeneutical phenomenology is that it is not simply describing parents’ experiences but reveals deeper meanings of their understanding of disability which provides for rich interpretive data. Another exemplary study using an interpretive phenomenological model is the work of Munroe (2015), who demonstrates the rigor involved in phenomenological traditions. She also identifies the need for research that focuses on individual experiences of African parents in the Western context and how they perceive their experiences (Munro, 2015). This finding illustrates the need and relevance of my research topic, which explores the subjective experiences of Ghanaian-Canadian parents of children with developmental disabilities through the use of hermeneutical phenomenology. This methodology helped to set the parameters of this research project.

Sample Size

Convenience and purposeful sampling were used to recruit participants based on availability and accessibility for this research (Creswell, 2014). Initially, I had hoped to recruit four to five participants but ended up with six participants who were interested in reflecting upon their experiences and understandings of raising a child or children with developmental disability. The sample size was limited to six purposively selected parents from different families who had children with developmental disabilities. Four of these participants self-identified as female and two identified as male. The relatively small number of participants was largely attributed to the limited time frame of this study and to partially address the gap pointed out by Munro (2015) who asserts that there is a need to study the individual experiences of African parents of children with developmental disabilities living in western countries. A relatively small sample size helped to capture the individual experiences of these six participants, but the findings cannot be generalized to the population of Ghanaian-Canadian parents of children with developmental disabilities (Creswell, 2014; Good Gingerich, 2019). These participants had to meet the inclusion criteria in order to participate in this research.

Inclusion Criteria

This study was limited to Ghanaian-Canadian parents or caregivers from different families who are first-generation immigrants that came to Canada as adults and have been residing in the province of Ontario for seven or more years. This was to ensure that the parents had an adequate acculturation process in the Canadian atmosphere to allow for substantial experiences within the Ghanaian and Canadian cultures. In order to participate in this study, parents should have a child or adult who was formally diagnosed at least five years ago.

Ghanaian-Canadians within this research project will represent first-generation parents that have migrated to Canada and are currently living in the province of Ontario.

Included in this research criteria were sole support parents who can either be male, female, queer or gender non-binary, and including heterosexual, same-sex and trans couples who identified as Ghanaian. Participants were asked to select a pseudonym at the beginning of this project. The following information was collected upon my initial contact with participants: names; contact information; if his/her/their child has an official diagnosis of a developmental disability; how many years the child has had this diagnosis; how long the parents have lived in Canada; and whether they are first-generation Canadians.

Recruitment

To recruit participants for this study, I used word of mouth to convey my research interests and established a contact within the Ghanaian-Canadian community with whom I did not have a personal relationship. My contact person was a Child Protection Worker and identifies as a second-generation Ghanaian-Canadian without children. This person was given flyers and asked to distribute them. The flyers included an outline of the criteria of the study, a brief introduction about me (the principal researcher), a general description of the study, confidentiality, along with my contact information, asking potential participants to call or e-mail me if they were interested. The flyer also stated that parents/caregivers would receive a \$20.00 cash honorarium to thank them for their participation. Once participants started contacting me, I asked for their name and contact information. I reviewed the inclusion criteria with the parent or parents along with the details and requirements of the study as outlined in the informed consent form which also permitted me to record the interviews.

My contact was able to provide me with three potential participants who have a shared experience of raising a child with a developmental disability. In order to secure more participants for this study, a snowballing technique was used to ask parents to recommend participants who share similar experiences and met the inclusion criteria. I provided these parents with extra copies of the flyers and was able to recruit two additional participants for this study.

The participants and I selected a mutually agreed upon location to meet for the interview. The majority of the participants chose to meet in their homes and provided me with their address during the initial contact. One participant and I agreed to meet at her place of employment where she secured a meeting in a private room where the interview could take place. Prior to meeting with this participant, I discussed the limits of maintaining confidentiality given the space in which we were meeting, which she agreed with.

All participants opted to call me and I used this as an opportunity to build rapport with these parents through shared interests and cultural background. It was important to share my interest in this topic while being mindful of influencing participants' responses to the interview questions. I felt that sharing my personal experiences helped to draw parallels between myself and participants as well as minimize any tensions or barriers between the researcher and participant. Participants recruited for this study resided in the province of Ontario and lived predominately in the Greater Toronto Area, while others lived on the outskirts. On the day of the interviews, I reviewed the informed consent and duty to report measures form with participants and they were asked to sign it to give their consent. The first participant was not comfortable accepting the \$20.00 cash honorarium that I gave her at the end of the interview. I decided to change the honorarium to a \$20.00 Starbucks gift card and participants appeared to be more receptive to this token of appreciation.

Data Collection

The data for this study was derived from interviews, participant observations and field notes that included personal reflections that I wrote shortly after conducting interviews. In the realm of human science, empirical methods, such as interviews and observations, are used to gather the interpretive meanings of people's experiences (Adam & Manen, 2008). In keeping with the phenomenological traditions, I conducted face-to-face in-depth semi-structured interviews, using open-ended questions. These questions were posed to a sample size of six Ghanaian-Canadian parents who were invited to share their understandings and experiences of raising a child with a developmental disability.

A less formal method for the interviews allowed for rapport between myself and the participants, while minimizing some of the tensions that accompany more formal and structured interviews. For example, some individuals may become more nervous and less incline to share their experiences in a formal interview. My decision for using a less formal interview method was also influenced by a desire to minimize any power imbalances that may have existed between myself and the participants and vice versa.

The use of observations helped me to assess parents' intentions and the level of comfort parents had with the questions by observing body language, tone of voice, use of language (or any hesitation), facial expression and so on. An interview guide was created with questions that would be posed to participants who were asked to reflect on the following seven questions that reveal their understandings: These questions were;

1. What would you say your understanding of disability was prior to having a child with a developmental disability?
2. Did any experiences or encounters make you feel or think this way?

3. How would you describe your present understanding of disability or developmental disability?
4. Did moving to Canada affect your understanding in any way?
5. What are some of the daily challenges that you experience raising a child with a developmental disability?
6. Was there anything that you did not expect? Any surprises?
7. If you had a final message for people within our society about your experiences, what would that be?

On average, the interviews lasted approximately one hour and twenty minutes, with forty minutes devoted to building rapport, reviewing informed consent and answering any questions from participants. The remaining forty minutes were devoted to the interview where participants responded to questions from the interview guide. The time frame of the interviews assisted me in generating rich descriptive data for analysis.

Data Analysis

The data analysis employed a hermeneutic cycle. According to Lavery (2003) “this requires the researcher to read, reflect and interpret” and continuously do this until themes are generated (Lavery, 2003 in Kafle, 2011 p.195). After each interview was completed, I set aside approximately one to two hours to reflect upon interviews, followed by transcription of the data. The reflexive writing process was not only limited to the time I spent engaging with the data, but there were instances where my initial perspective or interpretation would change and I would document this to demonstrate the layers in my interpretations. I later transcribed each interview verbatim using a text to speech feature on my laptop that made for quick and accurate

transcription, with an opportunity for me to reflect on the interviews while transcribing. After all transcriptions were completed, I spent time familiarizing myself with the data, which meant reading and rereading transcripts daily to establish patterns in the way in which participants explained concepts related to disability and statements that captured their understanding and experiences. As I read each interview, I kept track of the terms, themes, or concepts that resonated with me and documented my thoughts on these formulations. After each reading, I established themes and subthemes revealed by each participant. This process helped me to establish themes and draw connection and distinctions between participants. Once themes were established I reviewed them periodically to see if any other thoughts or understandings emerged. I selected relevant excerpts from each participant that spoke to the various themes that were generated which helped me to stay organized.

A second partial transcription was conducted where I edited and omitted repetitive phrases such as “umm” and “ahh” from some of the excerpts that I had selected that coincided with the themes. These statements were omitted only if they did not add any meaning that were being conveyed by participants. However, in some cases, I reverted to the raw, unedited data because such phrases signified something significant to me. For example, some participants used “umm,” which, coupled with their body language and tone of voice, signified hesitation. I also thought about how removing these mundane terms may also skew the meanings that parents were trying to convey. When transcriptions were completed, a separate document was created to chart the themes that resonated with me from each interview.

I reflected on some of the terms and narratives that participants used and how I understood them. While reflecting and interpreting, I paid attention to what was said, what was implied, and how bodies responded, which helped me get to a deeper understanding of

participants' experiences and understandings. A further reading of the transcripts helped me to organize and highlight specific sections from participant interviews that spoke to my research question. I repeated this cycle with each participant interview and began to see shared themes between all the participants that were both similar and distinct from the literature assessment conducted previously. The process of transcribing, reflecting, and interpreting the narratives and responses to the interview guide began to reveal the essence that Ghanaian-Canadian parents attributed to having children with developmental disabilities. This helped to shift the data which was analyzed and will be discussed at length in chapter four. Given that the nature of the hermeneutical cycle is embedded in reflexivity, I decided to interweave my reflections throughout the findings and discussion section of this research. This was done to show my engagement with the data as well as illustrate my own learning.

Ethical Considerations

The probability of harm occurring in this research was minimal. Since discussions around a child's diagnosis and a parent's experiences can be a sensitive and emotional topic, I anticipated this to be a potential trigger. During the interviews, parents were advised of counselling services in the event that they needed them. Parents were also informed of their right to withdraw from this project at any given time. To ensure confidentiality was maintained, Ghanaian-Canadian parents of children with developmental disabilities were asked to select a pseudonym, and told that they would be assigned a code at the beginning of this project, which was applied to all the data collected from respective participants. Any identifying information collected from participants was replaced with the established code.

During one interview the participant became emotional and began to cry when talking about some of her experiences raising a child with a developmental disability. After the interview was completed I offered counselling services to ensure that she was able to speak to a professional and was not harmed during this process. This participant declined counselling services and as the researcher, I followed up with her the following day to make sure she was fine and offered counselling and she declined.

Data Storage and Management

A master list was created with the codes and participants' names, dates and interview times and was locked away in a lock box. Also, information pertaining to family composition, where participants reside and any other identifying characteristics was withheld. This was done to ensure that information was organized, and that confidentiality is maintained throughout the research process. All information supplied during the research will be held in confidence, and unless requested, pseudonym names will appear in any report or publication of the research. All data was stored and managed under the selected pseudonym.

Data was collected through handwritten notes, audio tapes and digital devices. All data was stored in a locked facility; hardcopy materials (notes from interviews and audio recordings) will be locked away in a lock box secured with a key. Electronic data was secured through passwords and only the researcher was the person to have access to this information. Participants were advised that data will be stored until April 30th, 2020 in a secured location. Hard copies of all documentation will be placed in a secure box for shredding. Electronic information will be deleted from computer hard drives and recycle bin. Also, I anticipated that meetings would be held in spaces where parents will feel comfortable, with two potential spaces being in

participants' homes and in public libraries, with the researcher securing private rooms to ensure anonymity and confidentiality. During the course of interviews, five participants opted to meet in their homes while one preferred meeting at their place of employment.

Chapter 4: Findings and Discussion

This chapter presents the findings of my research, followed by a discussion of these findings. Four major themes emerged from this research, all of which reveal the essence of these participants' understandings and experiences. These themes are: a) A broad understanding of disability; b) The influence of experiences in Ghana and Canada; c) Emotional responses and challenges; d) Protective factors. The findings are charted below with examples that are organized as subthemes.

To begin, I have charted the demographics of the participants who agreed to participate in this study, while major themes and subthemes are listed below.

Demographics

No.	Pseudonyms	Gender	Sexual orientation	Years living in Canada	Marital status	Child's Diagnosis
1	Anna	Female	Heterosexual	25 years	Divorced	Dual diagnosis
2	Peter	Male	Heterosexual	35 years	Married	Autism
3	Nancy	Female	Heterosexual	25 years	Married	Autism
4	Alice	Female	Heterosexual	22 years	Married	Autism
5	Mike	Male	Heterosexual	25 years	Divorced	Global Developmental Delay
6	Grace	Female	Heterosexual	10 years	Married	Dual Diagnosis

<u>Major themes</u>	<u>Subthemes</u>
A broad understanding of disability	<ul style="list-style-type: none"> • Biopsychosocial model • medical • Natural occurrence
The influence of experiences in Ghana and Canada	<ul style="list-style-type: none"> • Back home • Positive and negative responses to my child • Stigma and isolation
Emotional responses and challenges	<ul style="list-style-type: none"> • The normal child • Stress and frustration • Worries about the future • Joy and happiness
Protective factors	<ul style="list-style-type: none"> • The use of faith and spirituality • Thirst for knowledge

One observation that I made as parents selected pseudonyms for the purposes of this study was that the names selected were predominantly Eurocentric names. This may have been an additional feature of confidentiality that these parents came up with, or it may suggest integration into Western societies as participants have been in Canada for many years. In preparing for the data collection process, I felt it necessary to document the bias and assumptions

that I held about this research project. As a second-generation Ghanaian-Canadian, I was aware of the state of persons with disabilities in Ghana through stories that I was told as a child. However, I did not have exposure to people with disabilities prior to moving to Canada. In Canada, I was exposed to the discrimination these individuals faced in the school system.

From my observations, children with disabilities were ostracized in “special education” classes while the rest of us were free to interact with our normal peers. I watched as children were made fun of and teased for their differences, and this became normalized as a way that people with disabilities were treated in society. These “special” people were subject to special treatment that limited their participation, and for me, it was something to be ashamed of. When I received news of my brother’s diagnosis, I felt a sense of shame and rarely talked about my brother to my peers. I could not reconcile how I was feeling, and what I had observed in school would subsequently be the same treatment that my brother would experience in his life. Over time, I began to realize that there was something inherently wrong with this, and I began my own journey to unsettle these feelings. This continues to be an everyday battle for me.

Going into this research, I was aware of the stigma that people with disabilities face and I was disheartened by this. I expected to hear similar stories from parents of children with developmental disabilities. Given that I was interviewing participants who grew up in Ghana and later migrated to Canada, I assumed that parents would ascribe to a ‘religious worldview that saw disability as a punishment or a curse’ which would guide their understanding, a common assumption shared by various scholars (Avoke, 2012, 2002; Abang, 1988; Oti-Boadi, 2017; Badu, 2016). This was due to the stories that I heard growing up and due to my early experiences in Canada with my community who in some cases ascribed to this view.

I was unsettled by some of the experiences shared with me during the course of this research project, and as a sister of an individual with a disability, I was often angered by the discrimination that these parents experienced. At certain points, I was saddened by some of the experiences of isolation, but at other points, I was met with a sense of hope for the future and what we could learn from each parent's experiences. The process of collecting data was filled with emotions and relationships that far supersede this project. Below are the major themes and subthemes that emerged from this study, which will be followed by excerpts from participants.

Theme 1: A Broad Understanding of Disability

The participants had diverse understandings of a developmental disability. These understandings formed a biopsychosocial model, a medical model, or a naturalistic model. Although some participants clearly stated that they ascribed to a medical worldview, a closer reading of the whole transcript revealed a biopsychosocial model.

Biopsychosocial model.

Parents situated their understanding of disability within a biopsychosocial model that captures a holistic view of the medical and social factors associated with disability. Illustrations from Mike and Nancy are examples of participants understandings.

In terms of disability I've always seen it is something that was due to a birth defect or any kind of condition and the child or anybody that limits their ability to function normally . . . The Society has actually placing barriers, that prevents them from functioning, so what's up me as a parent to be their strong advocate. – Mike

Oh, now I understand that there are, um, medical factors, psychological factors, so it could be chemical and balances, they're still doing research about autism, I don't know where they landed... I don't know if it's environmental or genetic causes, I'm not sure. –Nancy

Fewer participants shared understandings that reflected a medical worldview that viewed disability in terms of functioning as a way of fitting into society. An example from Alice illustrates this.

Medical model.

People with different functioning levels...(Alice)

Mike stated that his understanding of disability was situated in a medical worldview. “Being defective” alluded to a medicalized view that in some ways suggested that people are manufactured and therefore can be fixed. In a similar interpretation, Nancy revealed multiple factors that can contribute to a diagnosis of a developmental disability; the uncertainty in her response led me to believe that the causes of disability are elusive within the medical and research community in spite of the extensive research that has been done. She shared this in her journey to find answers to the causes of her son’s disability by doing her own research, contacting family members in Ghana to determine if there is a history of disability in her family that can be traced to genetic causes.

However, in analyzing the experiences of Mike and Nancy, it revealed a broader understanding that complemented a biopsychosocial model as they both discussed attitudinal barriers and minimal accommodations that their children received. This aligned with the World Health Organization’s (WHO) (2011) view of disability that focuses on the biological and environmental factors that not only influence disability, but the experiences associated with an individual’s disability. Both participant views fit with Shakespeare’s (2006) claim that it is society that disables persons with disabilities, rather than the condition itself. Recognizing that

barriers exist that cause persons with disabilities to be pushed to the margins, these barriers are a driving force for oppression of persons with developmental disabilities and their caregivers within society.

Alice summed up her understanding in this statement, which posits that the extent to which an individual is able to function is hierarchical and categorical. A “lower level of functionality” means that an individual with a developmental disability needs more support in society from parents and caregivers, while a higher level of functionality is associated with independence. This sense of independence is based on an individual’s ability to care for themselves, i.e. cook, clean, provide personal care, get married, and interact with others within their various communities. She recounted this in her early experiences in Ghana as well as in the supports that she provides for her son that are oriented toward increasing his levels of functionality in the said domains.

Alice’s view on developmental disabilities revealed a medical orientation towards disability. Her views are similar to those described by Sloper (1998) and Bricout (2004), who explain that since the first point of contact for parents is the medical field, parents are more likely to hold a medical view of disability that looks for ways to fix the impairment. Fixing her child meant helping him to develop the skills necessary to be a functioning member of society; the higher he was able to function, the more integrated he would be.

Naturalistic model.

Two of the participants viewed disability as something that was a natural phenomenon. Participants shared their understanding in the ways they treated others, and in the supports that

they provided for their children. The responses given by both Peter and Grace speak to this understanding.

I mean, disability is a natural thing and can happen to anybody. I don't look or think about people any differently because of their disabilities. –Peter

I don't want any medication because of hyperactivity or anxiety or aggression or any challenging behavior. I want [my child] to respond naturally, trying to do ABA therapy because it's a natural thing. –Grace

Peter and Grace shared similar views on this notion of developmental disability in their comments. A developmental disability is something that these parents have normalized as a natural occurrence that cuts across the lines of race, social status, gender, class, sexuality, and so on. Peter arrives at this understanding in part due to his professional experiences prior to having a child with a developmental disability. This outlook was supported by the policy changes and measures he took in a supervisory role. In her interactions with service providers, Grace recalled being offered medication by various service providers to address her son's challenging behaviours. She rejected these offers as it contradicted her worldview of disability and opted for a more natural approach using therapeutic interventions. Peter and Grace challenge the view of Sloper (1998) and Bricout (2004), who states that disability can be fixed using prescriptive methods. However, in seeking a more natural approach, Grace also reinforces a medical worldview in the sense that therapeutic interventions can also be depicted as a form of fixing what is viewed as natural. The tension that exists between participants' understandings captures the diverse worldviews when it comes to some Ghanaian-Canadian parents of children with developmental disabilities. These understandings are situated in both a Ghanaian and Canadian context.

Theme 2: Contrasting Experiences Back Home and in Canada

When asked to reflect on their understanding of developmental disability, parents unanimously began by reflecting on experiences back home. Participants shared positive and negative experiences back home that paints a picture of the realities of women blaming and laughter and discrimination that people with disabilities faced in a Ghanaian context. The rich descriptions offered by Anna, Peter, and Grace illustrate some of these experiences.

Back home.

Back home, most of the time if you have a child with a disability, they tend to blame the woman. It's your fault! When you can't get pregnant, it's the woman's fault, it's not the man's fault. So if you have a child with the disability and you keep the baby, it's the lady's fault and it's not only her husband who was going to give her problems... it's his whole family, it's your fault, maybe you did something that came back to you and it's a curse or something. –Anna

I remember one guy in primary school back in those days. I'm just thinking about him now that you're asking me this question. I remember the guy . . . had Down syndrome. Yes, actually, people would always laugh with him because he was singing songs that are funny, they weren't laughing at his disability but what he said in those songs making us happy (smiling). –Peter

When we were in elementary school, I remember people with developmental disabilities, but we called them imbecile, yeah, we call them imbecile and there's no attachment to them and they are excluded from society. I didn't have any thoughts or even compassionate heart towards them, you know. –Grace

Anna analyzed the experiences of mothers in her rural community of Ghana who had children with developmental disabilities. She recalled memories of conversations that she had heard prior to coming to Canada. This experience suggested that mothers bear the responsibilities of producing a “normal child” who do not elicit behaviors that would draw undesired attention from others. The mother's inability to produce a disability-free child in a marriage is the site for blame from her partner and in-laws. This draws parallels with both Badu (2016) and Khanlou's (2017)

views that cultures that uphold values associated with having a normal child tend to disregard caregivers because the culture rejects those who stray from the norm. While sitting with Anna, I wondered how the treatment of women who had birthed a child with a developmental disability could also be attributed to notions of citizenship where women's bodies are valued on the basis of their ability to produce "normal" and productive citizens.

Although Anna's observations were positioned in a Ghanaian context, it mirrors the views of Critical Disability scholars and researchers who argue that cultural views can lead to blame and exclusion (Bricout, 2004; Buettgen, et al., 2015; Lalvani, 2015; Khanlou et al, 2018; Woodgate, 2008; Kinnear, 2015). The intersections of gender, disability and motherhood come into play as these women are marked by exclusion as a result of patriarchal norms and values that in some cases encourage oppression of women.

However, Peter recalled a different memory of going to school and being filled with joy, laughter, and a sense of belonging. As he described his interactions with an individual with Down syndrome, his face lit up with excitement and warmth. This experience confirms Abang's (1988) assertion that children with disabilities are a blessing in the lives of families and friends. Peter recalled this memory and confirmed his understanding of disability, and he also spoke of Ghana as a place where people are included and adorned in spite of their unique needs. Peter's recollection is at odds with the stories told by Grace in the sense that her memories revealed some of the discrimination that people with disabilities face in Ghana. Peter's view was a pleasant surprise for me to hear as I thought about discourses around disability that often focused on exclusion and oppression with minimal attention to the positive understanding of disability. I became accustomed to this way of thinking about disability so much that any positive experiences became foreign to me.

When I posed my first question about how parents understood disability prior to having a child with a developmental disability, all six participants shared experiences of back home, which was surprising to me given that most parents had been in Canada many years. This suggested two things to me: Canada is not a place that they consider to be home; and that to some extent, how they understood disability was rooted in a Ghanaian context. The ambiguity of not identifying Canada as home and yet ascribing to Canadian worldviews was puzzling to me. I wondered if there was something more than acclimatization that could explain this discovery. This revelation speaks to DuBois (2007)'s notion of double-consciousness where Ghanaian-Canadian parents of children with disabilities may struggle to reconcile their dual identities as Ghanaian-Canadians.

Responses to my child.

All the Ghanaian-Canadian parents in the study shared both positive and negative experiences. The availability of resources was an experience that left some parents feeling included. Other responses mirrored discriminatory attitudes that Grace and others discussed. The following quotations from Grace and Anna depict this.

But I noticed that in Canada there's more inclusion. As in from 0 to 18 years old the school... there's more of social inclusion in the school system right here in Canada than in the States. There's a lot of support and community help . . . They've given me a lot of support that I didn't even know existed out there. – Grace

I was in the hospital, [I] was just told that [my child] has Down syndrome and I was crying . . . one of my best friend's husband came to the hospital (voice escalated, visibly angered) and told me to give [my child] away and he's here in Canada and the statement he made was that you have kids to grow up and take care of you, if the child can't do anything why would you keep him? –Anna

Grace described her experiences shortly after migrating to Canada after residing in the United States for approximately three years. She drew a comparison between the educational system in the states to that of Canada and arrives at the conclusion that Canada is more inclusive when compared to the United states. Grace's comparisons are in line with researchers who argue that service providers' understanding of a child's disability and receiving appropriate supports led to a sense of inclusion (Greeff & Nolting, 2018; Davis, 2018; Depape & Lindsay, 2015, p.579; John et. al, 2015; Marshall & Long, 2010). For Grace, a seamless integration into the Canadian school systems provided for a more positive experience, whereas other participants shared divergent experiences.

Anna described a scene at the hospital shortly after she gave birth to her son and learned of his diagnosis. She was overcome with sadness which was worsened by the remarks that were made about her child from a close friend's husband and a fellow Ghanaian-Canadian who came to visit her at the hospital. This illustration mirrors the views of researchers who state that a visible disability in some cases revealed stereotypical attitudes and assumptions made about children that impacted parent's experiences (Corrigan et al., 2014; Khanlou, 2018; Badu, 2016; Oti-Boadi, 2017; Woodgate, 2008; Kinnear, 2015). The story that Anna shared with me was a depiction of public and social stigma that she experienced at the hospital as she struggled to reconcile emotions associated with learning of her child's diagnosis.

The experience shared by Anna supports arguments made by Agbenyega (2003), Avoke (2002), and Grue (2016), who assert that the label of disability signifies a difference that plays a major role in what is acceptable and unacceptable in society. Comments made by Anna's friends husband reveals a belief that caring for children with disabilities is unacceptable. It also implies that cultural understandings of disability influence how people with disabilities are perceived and

can be fixed through time and space for some Ghanaian-Canadian parents who may not have children with disabilities. Anna's experience also shows that disability can be a source of rejection in the sense that children with disabilities are not able to reciprocate the support given to them by parents when they were children. The assumptions that guide social perceptions of disability can be daunting.

Hearing Anna's story had an impact on me and I thought about whether asking parents to recount their experiences was too painful and emotionally stirring. I also took it as something that parents might want to share as it would cause others who might be reading this to consider the ways in which they may conceptualize disability and parenting.

Grace and Anna shared similar experiences of supports received from the education system and talked about supports after children transitioned out of school. The experience described by Grace challenges the assertion that it is society that disables persons with disabilities through exclusionary practices (Shakespeare, 2006). What Grace shares is her definition of inclusion, where her son would get accommodations and access to services to address his complex needs. That is, the very means by which Shakespeare takes persons with disabilities to be excluded, Grace believes is inclusive.

Both Grace and Anna shared the positive experiences of the supports that their children received in elementary and high school, that led me to believe that younger children were more inclined to receive accommodation as compared to those who were over the age of eighteen. I was surprised by the limited to nonexistent supports that children received after they turn eighteen. I came to realize that the experiences of parents were informed by the age of their child, since younger children and their families received more support when compared to adults with developmental disabilities and their families. I wondered: if children identified as having a

developmental disability had received supports, was the expectation that at the age of eighteen the disability would be fixed or non-existent? Or would the responsibility be placed solely on the parents, absolving systems of support of any responsibility? Perhaps future research can explore the difference in experiences for the various age groups.

Stigma, attitudinal barriers and isolation.

In contrast to Grace's experiences, many participants shared stories of stigma that led parents to feeling isolated from their various communities. These experiences reflected societal attitudes and isolation that influenced parent's perspectives. Anna, Alice, and Mike's descriptions illustrate this.

I remember one time going to Sick Kids [Hospital] . . . We are waiting for the car . . . He doesn't like crowded places. So, we are waiting and he was like eight or nine years old and he is screaming because we are in Tim Hortons and there's a lot of people . . . This lady starts screaming, "Shut up! Shut up! Keep quiet, stop crying!" . . . I didn't say anything. [visibly angered] Then she had the nerve to approach him saying, "You're a bad boy, why are you crying like that?" [alters voice] "What's your name?" I still didn't say anything. So, she asked his name and I told her he doesn't talk. Then she said, "Oh, I'm sorry." I asked her, "What are you sorry for?" "Because he doesn't talk." You have been screaming at this child that you don't know, and you are sorry! Sorry for what! You're sorry because he can't talk, and I said to her, "I don't need your sympathy . . . There're a lot of kids with needs, and you could have walked up to me as a mother. Mother to mother, and asked me, "is there anything that I can do to help?" [starts crying] because sometimes the only thing that you need to hear is someone tell you let it's going to be okay. The person gives you a hug and tells you it's going to be okay. You know it's not going to be okay or it won't change anything but it calms you down. I told the lady, "Take your sympathy and leave. I don't need your sympathy, I needed your empathy." –Anna

One summer he went to the mall and on his way back, he decided to stop at the waterpark at the splash pad and was sitting on the benches while the kids and the parents were playing. As soon as he arrived, some of the parents became concerned and they felt that he was not supposed to be there and . . . took it upon themselves to call the police on him, saying that an odd looking person was at the

waterpark and they were worried about the kids . . . so the police came and the police officer realized that he had some sort of a disability, and the parents that were reporting him did not know. –Alice

Anna shared an experience of public stigma as she was waiting to be picked up after attending an appointment with her son. Anna's story was interesting and disheartening to me because she shared that her son's disability was one that was visible, and yet still comments were directed toward her son and not her. The story that Anna relayed to me was a prime example of microaggression where Anna's son was blatantly discriminated against as a result of his disability, making an already stressful situation more tense for Anna and her son. This incident pairs with Grue (2016) and Corrigan et al.'s (2014) understandings of stigma that state that disability is a label that signifies differences which are embedded in stereotypes and assumption about people with disabilities. Stigma in public spaces becomes an everyday experience, as each participant provided me with numerous examples of various types they experienced.

This led me to believe that such experiences were not isolated to Anna but spoke to a broader social problem of attitudinal barriers that serve to isolate and undermine children and parents. At the realization of disability, the mother automatically shifts to apologizing, as if to imply the lack of speech was an unfortunate tragedy for Anna. This mother's reaction supports the arguments made by Oliver (1990), who asserts that disability is often viewed as a personal and unfortunate tragedy that is the subject of pity. Anna vehemently rejects any offers of sympathy and shows strength in coming to the aid of her son. Anna's distinction between sympathy and empathy marked an important difference in meaning; while sympathy can reinforce a tragedy model of disability, empathy suggests understanding and compassion toward parents and their children. This view complemented that of Grace, who became compassionate

towards people with disabilities and other parents who shared similar experiences. A further interpretation was revealed which was twofold in the sense that Anna showed resistance in challenging a fellow mother who was now adorned with a lens of pity. This can also be said to be a prime example of disability microaggression where persons with disabilities are the subjects of subtle and blatant forms of discrimination (Davila, 2015). Anna's response when she defended her son can easily be misinterpreted as a reverse microaggression, where she is verbally attacking another mother who showed remorse for her actions. This notion of reverse microaggression is enmeshed with the stereotypes of being a black woman in a Canadian context who are perceived as being angry or too aggressive. This can be said to bear similarities with scholars who define blackness as being associated with savagery or unrefinement (Fanon, 1970; Bailey, 2018). In this interpretation, I came to the realization that in spite of the benefits of a hermenutical circle as an approach to analyzing data, experiences can also be misinterpreted in a way that may uphold racist ideologies, as Anna may have been perceived as being unrefined in her response.

Emotions of anger were met with sadness, pain and tears as Anna wept while telling me this story and I became concerned for Anna's wellbeing. To ensure that Anna did not suffer any subsequent harm, I offered counselling services as an additional support. Anna and I continued to talk after the interview was completed until I was assured that she felt better. I called Anna the next day and again offered counselling services to see if there was anything more I could do. Anna refused any offers of counselling that I offered her. However, through this interview, I have established a relationship with Anna and the other participants that will far supersede this project as each participant shared intimate details of their lives, which to me was a privilege.

Alice on the other hand describes her son's disability as being invisible. He is relatively tall and large, which may draw attention to him in public spaces. His appearance was a cause for suspicion and threat to parents and their children at the waterpark. I wondered what made him suspicious to these parents who were obviously trying to protect their children from what they perceived to be a threat. Was it the fact that he was tall and heavy set, or was it perhaps his race that made him appear threatening? If her son was white, would the outcome have been the same? Would he be a person who appeared "suspicious"? For Alice, her son's visit to the water park raised suspicion from the parents who were there with their children.

Historically and contemporarily, whiteness has set the bar in which other minority or racialized groups have been judged, and anyone who deviates from this standard is rendered suspicious, a threat, or even barbaric (Gillborn, 2015; 1967; Bailey, 2018; Lorde, 1984, hooks, 1992; Davila, 2015; Delgado & Stefancic, 2001). Alice was forced to limit her son's independence to places where she would be available to supervise him. She saw this incident as a threat to her son's safety and wellbeing in the community. This incident forced Anna to continue to support her son by helping him to function beyond his basic needs which would allow him to live independently.

Race was not a prominent feature in this study, however, as a black woman, I am forced to see race and racism as it is embedded in my epistemologies. However, I didn't focus on this until my supervisor sent me a publication that shifted my engagement with the data analysis (Kinross, 2019). I thought about why race was not apparent to me? Was I unaware of issues of race in a Canadian context? I concluded that, in most cases race and racism was something too painful to talk about, however, it was a painful truth in my life as well as the lives of these

participants and it needed to be revealed. For Alice's son, race, height and body composition were intersecting factors that may have made disability elusive

Theme 3: Emotional Responses and Challenges

All Ghanaian-Canadian parents of children with developmental disabilities described desires of a normal child, stress and frustration, and worries about the future. However, other parents felt that the experience of raising a child with a developmental disability brought happiness and joy to their lives. The following comments support this finding.

A normal child.

Many of the participants that I interviewed made statements that echoed desires to have a normal child. Nancy and Anna provided an in-depth depiction of some the desires that parents had.

I was never thinking that I would have an abnormal child... I had to deal with it and it was like you have a child you feel like your child died or you don't have a child. So, I went through all the stages of sort of death. First, I thought I was seeing things... all the way to getting angry and asking why me? –Nancy

I didn't choose to have a child with developmental disability, I got it so I have to do everything that I can to make him feel normal. –Anna

Having a child with a developmental disability was not what parents envisioned for themselves, and the subsequent shock brought on feelings of loss and anger. Mourning the loss of the normal child bared resemblance to the participants in Zechella & Raval's (2016) study that referred to the parents' reaction as a state of grief where they could not reconcile their feelings and emotions towards disability. The confirmation of developmental disability triggered mourning for some parents as they questioned why they had a child with a developmental disability. Nancy shared that this led her in search for answers which involved looking at her

family history to see if it was prominent, doing research, and so on. The death of a normal child and the appearance of a child with a developmental disability made things challenging for her to come to terms with. Death then becomes associated with disability as something undesired and unwanted by parents – a fear of the Other.

For Anna, the idea of being normal was associated with a feeling that one has. Having her child feel normal involved providing him with emotional support, social support, and resources. Anna also thought it was important to feel a sense of belonging, love and acceptance. As did Nancy, though she initially struggles with this, she becomes more compassionate towards persons with disabilities and their caregivers. The notion of acceptance was similar to that of Burrell, et al., (2017) and Ennis-Cole et. al (2013), who argue that acceptance was a journey that involved initial feelings of embarrassment. These feelings were worthy of further study as I will discuss below.

Stress and frustration.

In addition, Nancy and Anna's sincerity and honesty captures the situations that further complicate feelings of shame, stress, and embarrassment. They share that:

It was just like, I felt some sort of embarrassment or shame . . . at the beginning . . . I feel guilty that we kept going to [places and were] always leaving him behind.
–Nancy

As soon as they turn eighteen, everything is gone. You don't know where to go, you don't know how you're gonna do everything, it's so stressful that it keeps you up [at night]. The other day I was thinking what do I do, do I work part-time or do I just go to work and then give all the money to them . . . [sighs] Either way, I can't keep him home. Even if I hire somebody to stay home with him, I'm still going to have to pay \$20 an hour, it's eight hours, that is \$160 a day . . . all these issues come up and it's not only the child you have to deal with, it's all the things that come with it . . . You don't have any help anywhere, you can't get the help and that is the cheapest . . . some of them go up to \$140 a day and I'm not rich, and if I was rich, fine, but I'm not rich, so even the \$60, it's hard for me. You

have to find something for him that is rewarding for him. To go to a program, make friends while I go to work. –Anna

Nancy articulated her feelings of guilt, shame, and embarrassment when she discovered that her son had a disability. The thoughts and feelings expressed by Nancy correlated with Corrigan et al.'s (2014) definition of self-stigma that derives from having a label of developmental disability that they hold as being something that connotes shame. Regardless of this, Nancy challenges these feelings and focuses her efforts on finding answers and securing resources for her child.

Anna gave a detailed account of the stresses that she faces when it comes to accessing financial supports for her child. The resources would ensure that her child has an enriching life that allows him to engage with others in his community, build relationships to be included, and develop skills that will help him to succeed. She looked to the oncoming stresses of the future as she prepared for her son to transition out of the school systems where she will have to pay out of pocket for his day program. What became apparent is the financial burden associated with raising a child with a developmental disability. The burden of disability for some of the parents lies in the systematic responses to disability which made the experience of raising a child with a developmental disability a stressful one, particularly for those who cannot afford the high costs of day programs.

The findings line up with the assessments of researchers who note that structural stigma stems from policies and practices around disability that limits access and participation of persons with disabilities and their caregivers (Corrigan et al., 2014; Khanlou, 2018; Badu, 2016; Oti-Boadi, 2017; Buettgen, et al., 2015; Lalvani, 2015; Baffoe, 2013). I remember reflecting on my identity as a researcher, and for me this was not about merely collecting data and moving on to

the next participant, it was more about building relationships with people whom I value and respect. It was about bringing to light these painful truths that keep these parents' voices silenced and perpetuate exclusion through policies and practices.

I thought about how class came into view for me as Peter reported no concerns around accessing resources to support his child and how this was in tension with the experience of Anna. This was in part due to the flexibility associated with his employment. During my interview with Peter, he reflected on his positionality as someone who was privileged because of his role in management and the flexibility that came with it. This minimized any concerns for him, whereas this was not the case for other parents.

Worries about the future.

Five parents shared concerns about the future that revolved around caregiving and supports for their children. Mike and Alice illustrate this in their individual responses.

I think about what's going to happen to her when I'm not available...—Mike

What will happen if something was to happen to me, where will he be and who will support him? These are constant fears and they're still things that I...worry about till this day. —Alice

Ghanaian-Canadian parents were unsettled when they were talking about the future of their children if they were not able to provide support for them. Mike found reassurance in service providers; he was confident they will provide the adequate support when he is not able to.

However, Alice's worry stems from doing research to learn more about the experiences of people with disabilities. This challenges some of the parents in Burrell., et al, (2017) study who looked to the future with optimism that their children would obscure the categories of normal and abnormal, making way for new categories that can be envisioned. For parents like Alice, in

their quest, they discover histories of eugenics, institutionalization, and the abuses suffered by people with disabilities. These add to Alice's worries, given that ferritic shocks were still a prominent feature in some group homes that she was aware of.

It's the joy and pain: a bittersweet experience.

All six participants shared experiences about the joys associated with parenting a child with a developmental disability. Although there were painful moments, the overall experience was a rewarding one. Peter and Anna illustrate this.

You know, sometimes when you're getting older and all the other kids are gone, it can sometimes be less fun at home, but with him around it's a great joy to me and my wife (smiles) . . . Having him around, we laugh together, do stuff together, have fun . . . He adds to our happiness . . . (continues smiling). His presence has brought such great joy. –Peter

He brings me so much joy that sometimes me and my friend say that if we didn't have these kids, [laughing] maybe we wouldn't have lived up to this time, because it's the pain and the joy. They give you unconditional love. –Anna

The experience of raising a child can enrich relationships and familial bonds in the daily activities with children. His depiction recalled the discussions from researchers who note that having a child with a developmental disability strengthened their relationship by adding an additional layer of joy (Zechella & Raval, 2016; John et. al, 2015; Oti-Boadi, 2017). Peter shared some of the activities that he engages in with his son that bring him happiness, describing how church members, including peers, adults, and fellow congregation members, embraced his son.

This is distinct from Mike's experiences with Ghanaian-Canadian churches, where accommodations are limited and attitudes forced him to withdraw his children from some church activities. Peter's experience is reminiscent of the childhood memories of laughter and joy that he experienced around his school colleagues in Ghana. In addition, the joy that he experiences in his interactions with people with disabilities affected his experiences of raising a child with a

disability. For Ghanaian-Canadian parents of children with developmental disabilities, the day-to-day experiences and interactions with others contributed to their overall understanding and well-being.

As Anna reflected on her experiences, she was overcome with a sense of joy and pain, demonstrated in her tears and laughter. Anna recalled the painful experiences of people's attitudes and accessing resources that made raising a child with a developmental disability more challenging. In the same breath, she envisioned that the amount of joy in her relationships was lifesaving. This finding is supported by studies that found parents who have shared similar experiences of raising a child with a developmental disability found the experience fulfilling (Burrell et al., 2017; Bunner, 2011; Oti-Boadi, 2017). Having unconditional love and building relationships with other parents brought about a sense of joy and community.

Theme 4: Protective Factors

Most of the participants talked about protective factors that helped them cope with the challenging experiences. Coping brought about a connection to their faith and inspired a thirst for knowledge.

The use of faith and spirituality.

A majority of the participants used their faith, mentioning God in their difficult times, and this was a consistent staple in the lives of participants. Anna, Mike, and Nancy's excerpts speak to this point.

I thank God that I have my child here and I also thank God that I can keep him. –
Anna

I put on my religious hat, they say whatever I want, I just pray to be consistent and I'll receive whatever you pray for –Mike

I have a deep belief in God. So, I turned to God because I was helpless at the time and yet I also went and utilized the resources available at the time. –Nancy

In spite of the obstacles and challenges with resources, including discrimination, Anna maintained her gratitude to God for blessing her with a child. Through the strength of God she was able to provide support to her son and remained hopeful. Similarly, Mike used consistent prayers to continue to support his children to be happy regardless of the circumstances. For Mike, his faith has brought about humility that made him thankful for the simple things in life. Nancy embraces her faith and relied on resources that are available to her to get through troubling times. She shared that after her initial struggles with her son's behaviours at church, she would take turns with her partner and family members to attend church. Now she is at a point where she has come to terms with her son's disability and is able to invite people into her home, and for her, this showed growth and maturity. The thoughts shared by Nancy support the views of Burrell, et al. (2017), who state that acceptance is a lifelong journey that an individual embarks on. For Nancy, this journey created a renewed sense of hope through her faith in God.

The remarks made by these parents challenge several assumptions made by scholars who believe that Ghanaians are influenced by the religious model that states that disability is a punishment or a curse (Oti-Boadi, 2017; Avoke, 2002; Baffoe, 2013; Badu, 2016). Although the participants and I spoke at length about the religious model, they rejected these views and redefined the meaning ascribed to a religious model. That is, for these parents, a religious model of understanding was quite different. They turned to their religious beliefs as a source of support rather than justification for ostracization. These Ghanaian-Canadian parents showed that cultural understanding of disability continues to be a contested terrain. This discovery challenged any

biases that I held approaching this study and revealed there are numerous ways of conceptualizing religion that help us to envision epistemologies around disability and parenting.

As I wrapped up interviews with participants, I thought about an inductive approach and the possibilities of generating theory that would support these parents' understandings and experiences and challenge notions of the religious worldview. I wondered how the various epistemologies of disability presented by these parents could also coincide with their spiritual faith.

Thirst for knowledge.

The experience of having a child with a developmental disability created a thirst for knowledge about disabilities. All six participants acknowledged that their experiences lead them to learn more about disability, become a resource for other parents, and also change their career path.

Examples from Alice, Nancy, and Grace illustrate this:

You find yourself learning, learning to be able to support him, learning to communicate better, learning to expose them to different things that will help him, learning to come up with a plan to teach him to become more independent like taking the bus by himself... I was capable, even having the knowledge to do these things... As I was learning from the clients that I supported, I was learning from that and helping to support my son and as I was learning from my son I was also using that learning to support other clients that I worked with. –Alice

I learned a lot about autism and other disabilities and I was able to help other people to as well. . . . Couples coming to me, mothers come. I saw this couple in my church and their child was running around and they are running around and I see them and they haven't gone for an assessment but I could see I could just see and it turned out they would all become autistic. –Nancy

It's kind of opened up my heart and my mind and I changed my career, to learn more about it. Just to kind of understand the problem that they're having, and how to help them, and how I can like to include them in a society. –Grace

In Alice's experiences of seeking knowledge about developmental disabilities, she found herself working to support other families and adults with developmental disabilities. This helped her not only to become well versed in matters pertaining to developmental disabilities, it helped to strengthen her communication skills, the insight that she gained from work was integrated to help her support her son to develop his functioning capacities to be more independent. Alice learned from her son, which allowed her to integrate with both the supports that she provided to her son and those of her clients. In the process of this, she became more confident about herself and her sense of self, as well as her own abilities.

The comments made by these participants were similar to the comments made by parents who were transformed through the experiences of raising a child with a developmental disability (Depape & Lindsay, 2015; Kayfitz, 2010). Much like her earlier experiences of learning about institutionalization and eugenics, she was able to broaden her worldview about disability through this experience.

Like Alice, Anna equally sought to acquire knowledge about developmental disabilities, and in the process, she became a resource for other parents who had no knowledge of disability. Her keen sense led her to be better able to identify early signs of autism in other children whose parents have not been aware of developmental disabilities. For Grace, having a child with a developmental disability compelled her to change her career path to learn about the ways in which people with disabilities can be included in society.

Through the recruitment process and in conducting interviews with participants, I realized that most parents had direct and indirect working experiences with supporting children and adults with developmental disabilities and their families in various capacities. However, what makes the participants in this study unique is that they had insight as parents as well as

insights through their experiences providing services. As I interviewed participants, it became more apparent to me that parents' experiences of having children with developmental disabilities propelled them to work in a field where they could be helpful to others. I was moved by the passion and enthusiasm that each parent brought to the interviews, which was similar to the passion I held about this research project.

Chapter 5: Conclusion

This study answered the question: how do Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability, and what experiences inform this understanding? The risks associated with this project were minimal; however, in my first interview, the participant was emotionally triggered. In spite of this, I continued, knowing that these parents had a story to share with the world and I wanted to facilitate this knowledge while being supportive. I offered emotional supports and made other participants aware of the resources available to them. The support that I rendered to these parents during these interviews helped to build a trusting relationship between myself and the participants.

Parents were asked to reflect on their experiences and respond to seven open-ended questions in semi-structured interviews that lasted approximately thirty minutes in length. One thing that I realized through my interviews was that I spent more time engaging with parents outside the interviews than actually conducting them. For example, one participant and I spent time talking about our children and strategies that we employed to ensure successful integration into the school system. In the process, I was not only learning about participants' views of disability; I was building relationships and I was learning about myself as a student researcher, an aspiring social worker, and a mother. Our connection as parents and Ghanaians drew on shared experiences and common interests that helped me to bond with these parents.

The findings of this research project showed that some parents understood developmental disabilities through a medical worldview that was accurately described by the work of Sloper (1998) and Bricout (2004). For some participants whose understandings initially appeared to be rested in a medical worldview, a closer reading revealed a broader worldview of disability that rested on the psychosocial model. Other parents rejected the medical worldview altogether. These parents viewed disability as a natural phenomenon that challenged the individual, medical, social, and biopsychosocial meaning attributed to disability (CDC, 2018; Oliver, 1990; Sloper, 1998; Bricout, 2004; WHO, 2011; Shakespeare, 2006). Other participants had a holistic perspective that was supported by research studies (WHO, 2011; Buettgen, et al., 2015; Lalvani, 2015; Baffoe, 2013).

Through this discovery, I appreciated hermeneutical phenomenology in “revealing the essence of meaning” in what was explicitly stated versus what was implied as participants shared their narratives and understandings of disability (Adam & Manen, 2008; Kafle, 2011; Anderson-Nathe, 2008). A great deal of research suggests that Ghanaian parents believe that their child’s disability was a punishment for a supernatural force (Avoke, 2002; Abang, 1988; Oti-Boadi, 2017; Badu, 2016). However, this was not the case for the participants in this research project. In fact, participants who did discuss their relationship to religion explained that it was a source of positivity and support. This could have been due to the length of time that participants have spent in Western countries. However, it could also be attributed to the fact that parents reimagined a religious worldview that used prayer and community support to get them through difficult times and maintain their humility, compassion, and empathy.

There were diverse experiences that informed parents’ understandings that stemmed from childhood experiences in Ghana and other experiences within a Canadian context. Within

these experiences, conceptualizations of public- and self-stigma emerged that mirrored the arguments of several researchers (Grue, 2016; Corrigan et al., 2014; Khanlou, 2018; Badu, 2016; Oti-Boadi, 2017; Woodgate, 2008; Kinnear, 2015). Parents experienced self-stigma that resulted in feelings of shame and embarrassment, stress, frustration, and worries about the future, while other parents experienced feelings of joy and happiness were all emotions that were associated with Ghanaian-Canadian parents of children with developmental disabilities. For participants who experienced public stigma and isolation, these resulted in attitudes and responses towards their children that were akin to racism and ableism. For example, Alice's son's encounter at the waterpark led to police involvement, and Anna's son's experience as they waited to be picked up from an appointment and were berated by a woman in the process.

In the findings and discussion chapter of this research project, I answered the question of how Ghanaian-Canadian parents of children with developmental disabilities understood disability and what experiences informed this. The findings reveal that parents of children with developmental disabilities understood disabilities broadly. Their understandings were situated in a biopsychosocial, medical, and natural models of disability as illustrated in the various responses provided by participants. Such experiences were influenced by positive and negative experiences in both the Ghanaian and Canadian contexts that brought about issues related to mother blame, stigma, and isolation that complicated matters for these parents.

In addition to this, emotional responses associated with raising a child with a developmental disability were linked to feelings of shame, embarrassment, stress, and frustration coupled with joy and happiness. These responses reveal issues around parents' desires for a normal child, structural stigma, and concerns about the future given the historical experiences that continue to pervade the current climate. For these parents, their faith and connections to God

helped them to get through challenging times and showed resilience. Overall, the experience of having a child with a developmental disability was filled with joy and pain that ignited a thirst for knowledge. This was gained through learning, research and a change in career paths. In acquiring insight into disabilities, Ghanaian-Canadian parents of children with developmental disabilities sought to share this insight throughout their participation in this research project.

I began this research with an inquiry into personal experience, and through interviews with six participants, and as I analyzed the data, I began to realize some of the shortcomings of hermeneutical phenomenology. Indeed, experiences can be interpreted and misinterpreted in ways that reinforce assumptions and stereotypical attitudes, particularly in the context of this study towards parents and their children with disabilities as well as towards black women and their children. In addition to this, various intersecting aspects of our identity, such as race, height, disability, gender, age, and size can create multiple forms of oppression in any given space. A hermeneutical approach by itself does not offer insight into intersectional oppression. As such, I felt that having a study that was informed by an intersectional framework rather than an inductive approach would have been more beneficial in capturing the nuances of parents' experiences and their children's subjectivities.

Nevertheless, it became obvious to me that one particular aspect of the participants' identity was important: the age of each child significantly influenced the child and their parent's experience. This was vivid in the case of both Grace and Anna, particularly in the experiences of Grace whose son was younger and Anna whose son was transitioning out of the school system with limited supports that shaped the view of raising a child with a developmental disability. This research project brought about an unanticipated revelation. Perhaps future studies can explore the experiences of parents of older children with developmental disabilities.

I had hoped for same-sex, non-binary, trans, or queer parents of children with developmental disabilities, but this study was limited to heterosexual parents who were either married or divorced. In spite of my hopes of getting people with more diverse perspectives, the reality remains that this research can be perceived as another way in which our ideas around gender and sexuality are maintained. Essentially, the views expressed here are of heterosexual parents of children with developmental disabilities and this was a limitation of this research project. As a researcher, I did not have control over the recruitment outcomes, but further attention to diversity in recruitment would be worthwhile for future studies. Being a fellow Ghanaian, I had access to people in my community that could help connect me with a contact person.

I am deeply connected to Ghana as it is part of my cultural identity. Reading scholarly work as it talked about what happened to children with disabilities was not as triggering for me as hearing it directly from parents with explicit examples. As a researcher and a mother, I had to make a decision on the discourses that I was willing to engage in, my relationship with participants, and the possibility of framing my culture in a manner that would shed unwarranted attention or be unethical. As a student researcher, I decided to exclude any personal suspicions or explicit details and focus my efforts on parents' individual understandings and experiences. This speaks to my power as a student researcher – to be able to omit from and add to this research based on my subjectivity. For the most part, connecting with participants based on shared identities of being parents helped to minimize any tensions and build relationships, which made the process of interviewing a bit easier.

In anticipation of concluding this research project, I sought a broader social view of the parents that I interviewed. Most of the participants acknowledged the fact that society has made

strides to address the needs of persons with disabilities. However, they believed that more discussions needed to be had in the broader Canadian and Ghanaian context to help minimize stigma and in a continued effort to create awareness. In addition to this, these parents felt that approaching people from a place of compassion and sensitivity went a long way in fostering a sense of belonging. In terms of structural changes, I think that policies that guide the allocation of resources and supports to children while they are in the educational system need to equally be transitioned in adulthood and day program. These programs would provide care, support, and community engagement for children with developmental disabilities. This would allow parents, particularly from lower socioeconomic backgrounds or those with minimal supports, to continue to support their children to live fulfilling lives and to be included in all aspects of society. One possible recommendation is to provide a universal day program much like a universal childcare that would be accessible to allow parents to receive support when needed, free of charge.

As social workers with a vested interest in social justice issues, it is partly our responsibility to align ourselves with these parents to create awareness about disability in our communities, while also respecting cultural understandings and educating from a position of compassion. By continuing to do research that includes minority groups and by continuing to speak about disability-related experiences, and the systematic barriers that pervade the lives of minorities such as of Ghanaian-Canadian parents of children with developmental disabilities, fuller integration can become a reality. Ultimately, there are various epistemologies of disability, and through this research, Ghanaian-Canadian parents of children with developmental disabilities added to this discussion by revealing their understandings and the experiences that inform them. From this research it can be said that the personal experiences of Ghanaian-

Canadian parents of children with developmental disabilities can be connected to broader social and systemic issues.

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Appendices 1: Ethics Certificate

PANEL ON RESEARCH ETHICS <small>Navigating the ethics of human research</small>	TCPS 2: CORE
<h1><i>Certificate of Completion</i></h1> <p><i>This document certifies that</i></p> <p>Linda Awuni</p> <p><i>has completed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE)</i></p> <p>Date of Issue: 28 September, 2018</p>	

Appendices 2: Flyer

Are you over the age of 18 and a Ghanaian-Canadian parent of a child with a developmental disability?

Has your child received a diagnosis of a developmental disability 5 or more years ago?

Are you a first-generation Ghanaian parent who is residing in the province of Ontario?

If you answered yes to these questions, I would like to invite you to participate in my Practice Based Research project. My name is Linda Awuni and I am currently pursuing a Master's degree in Social Work at York University.

My research is titled, **Raising Children with a Developmental Disability: Ghanaian-Canadian Parents Shed Insight**. The purpose of this research is to understand how Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability and the experiences that influence this.

I am looking for four parents from different families who are interested in taking part in the research project. If you agree, there will be a one-on-one interview with me, lasting approximately two hours. It will be audio-recorded with your permission. We will have an initial phone conversation which will include setting up a meeting time for a face to face interview. This interview will take place at a mutually convenient time and location for you and me. Following this, I will be in contact with you via phone to clarify any statements and to discuss the findings and outcomes of this study which will also be shared with the Faculty of Social Work.

Your participation is voluntary, and you can choose to withdraw at any time during the course of this project. All participants will be asked to select a pseudonym at the beginning of this study to ensure that confidentiality is maintained.

If you are interested or require further information, please contact me at awunlin2@yorku.ca or 647-996-7752.

A \$20.00 Starbucks honorarium will be provided to show appreciation for your time and participation.

Thank you for your interest.

Appendices 3: Informed Consent Form

Informed Consent Form

Date: Tuesday, December 11th, 2018

Study Name: Raising Children with a Developmental Disability: Ghanaian-Canadian Parents Shed Insight.

Researcher name:

My name is Linda Awuni and I am currently pursuing a master's degree in Social Work at York University. I will be the principal investigator for this research project. I can be reached at 647-996-7752 or via email at awunilin@yorku.ca.

Purpose of the Research:

The purpose of this research is to gain insight into how Ghanaian-Canadian parents of children with developmental disabilities understand their child's disability and the lived experiences that influence this. The research uses hermeneutical phenomenology that focuses on the experiences and understandings of individuals through the stories that they tell. This Practice Based Research Paper will fulfill the thesis requirement for the masters in social work. The completed document will be submitted to the Faculty of Social Work for grading and storage.

What You Will Be Asked to Do in the Research:

Participants are responsible for selecting a pseudonym at the beginning of this study and meeting the researcher (Linda Awuni) at a mutually convenient time and location for a two-hour interview. Participants are asked to reflect upon their experiences and respond to open-ended questions posed by the researcher. To show appreciation for their participation in this research project, participants will be given a \$20.00 cash honorarium at the beginning of this interview.

Risks and Discomforts:

This research involves minimal risk. Speaking about lived experiences and a child's disability can sometimes be uncomfortable and may lead to participants becoming emotional. To minimize this, counselling services will be provided if or when the need arises.

Benefits of the Research and Benefits to You:

This research will benefit participants by contributing to self-awareness in recognition of the expert knowledge that they bring that is necessary in the field of research, Social Work and education. This research is in partial fulfillment of my Master's in Social Work. It will also help to enrich my learning around disability related issues that exist within the Ghanaian-Canadian communities. I anticipate that this research project will help to create an awareness of the experiences of Ghanaian-Canadian parents, foster a sense of inclusion and bridge the

existing gap in research pertaining to the interpretations of Ghanaian-Canadian parents of Children with developmental disabilities.

Voluntary Participation and Withdrawal:

Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of the ongoing relationship you may have with the researcher or the nature of your relationship with York University either now, or in the future.

If you decide to stop participating, you may withdraw without penalty, financial or otherwise, and you will still receive the promised honorarium.

In the event you withdraw from the study, all associated data collected will be immediately destroyed. Should you wish to withdraw after the study, you will have the option to also withdraw your data up until the analysis is complete.

Confidentiality:

Your information will not be assessed with identifying information. Participants will be asked to select a pseudonym or a code will be assigned at the beginning of this project which will be applied to all the data collected from participants. Any identifying information collected from participants will be replaced with the established code. A master list will be created with the codes and participants names and will be locked away separately in another lock box. This will be done to ensure that information is organized, and that confidentiality is maintained throughout the research process. All information supplied during the research will be held in confidence and unless you request, your pseudonym/name will appear in any report or publication of the research.

Data will be collected through handwritten notes, audio tapes and digital devices. Your data will be stored in a locked facility; hardcopy materials (notes from interviews and audio recordings) will be locked away in a lock box secured with a key. Electronic data will be secured through passwords. The principal researcher will transcribe audio recorded interviews and will be the only person to have access to the information.

Data will be stored until April 30th, 2020. Hard copies of all documentation will be placed in a secure box for shredding. Electronic information will be deleted from computer hard drives and trash can. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research?

If you have questions about the research in general or about your role in the study, feel free to contact me at awunilin@yorku.ca or my supervisor, Luann Good Gingrich at luanngg@yorku.ca and/or (416) 736-3600 ext. 20028. You may also contact the Graduate Program in Social Work at gssowk@yorku.ca and/or (416) 736-3600 ext. 20498.

This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols 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, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I _____ consent to participate in Raising Children with a Developmental Disability: Ghanaian-Canadian Parents Shed Insight, conducted by Linda Awuni. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____
Participant

Date _____

Signature _____
Principal Investigator

Date _____

Additional consent (where applicable)

1. Audio recording

☐ I consent to the audio-recording of my interview(s).

Signature _____
Participant Name:

Date _____

Appendices 4: Interview Guide

Interview Guide

1. What was your understanding of disability prior to having a child with a developmental disability?
2. Did you have any experiences that made you think or feel this way?
3. What is your current understanding of your child's disability?
4. What are some of the daily challenges that you experience raising a child with a developmental disability?
5. What are some of the positive experiences that from having a child with a disability?
6. Was there anything that you did not expect?