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**Securing a Successful Future for Children with Developmental Disabilities in Ghana and
Zambia: A Mixed-Methods Study of Parental and Service Provider Expectations**

A dissertation proposal document submitted in partial fulfillment of the requirements for
the degree of Doctor of Philosophy at Virginia Commonwealth University

By: PRINCESS-MELISSA WASHINGTON-NORTEY

M.S. Virginia Commonwealth University, May 2018

Director: Zewelangi Serpell, Ph.D.
Associate Professor of Psychology
Department of Psychology

Virginia Commonwealth University
Richmond, Virginia
May 2020

Acknowledgements

This multi-country, mixed methods project could not have been accomplished without the immense support of several individuals and organizations. During my academic journey, I became acutely aware of the importance of having a good academic advisor and I couldn't be more grateful to have had Dr. Serpell as my academic advisor! She had faith in me, and tirelessly worked with me on this, and several other projects throughout my academic training. I will always cherish our discussions about research ideas that always left me inspired and motivated to achieve my ambitious dreams.

I am also very grateful to my collaborators in Ghana and Zambia for their support during this process. My experience in Zambia was phenomenal! I finally got to sit at the feet of Prof. Robert Serpell and glean from his wisdom! Oh, how I enjoyed our meetings. Special thanks also go to Dr. Nabuzoka and Pyopyo Pelekamoyo for their insight into the Zambian culture around children with disabilities and their help with data collection. In addition, I am also grateful to my professor and long-time friend, Dr. Adote Anum, at the University of Ghana, for his continued support throughout my academic training. I also acknowledge and appreciate the support of all the special and general education centers in Ghana and Zambia that provided me with access into their institutions for data collection.

This project involved primary data collection that would not have been possible without travel to each of these countries. Dr. Terri Sullivan, my secondary advisor and employer at the time made this possible. I am grateful for her flexibility, encouragement, and financial support of this project. I also received funding from the Society for the Psychological Study of Social Issues (SPSSI) and VCU which I deeply appreciate.

To my committee members, Drs. Marcia Winter, Wendy Kliewer, Yaoying Xu, and Jennifer Accardo, I also express my thanks for their thoughtful appraisal of this work and the

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critical feedback provided that enhanced its quality. Each committee member, brought a unique perspective to the project that helped with determining the appropriate target sample, collecting the data, and analyzing the results. They were also available for consultation whenever I needed it and encouraged me to continue working even after the COVID 19 pandemic made staying focused more challenging.

Last but certainly not least, I am grateful to God, my family and friends for their support. God is my anchor and strength. He began this journey with me and sustained me through it. As I embark on the next phase of my life, I am confident in the fact that He has already gone before me and will be with me every step of the way. I am also grateful to Him for all the people he has brought into my life so far. I could not have asked for a better network of friends and family during this process. And although, wisdom cautions me to refrain from listing names at this point—for fear of forgetting someone—I cannot end without writing a special note of thanks to my sister, Nally. Nally, thanks for being my biggest cheerleader, my personal assistant, and the best human relations officer I know! Thanks for listening to me and encouraging me during the difficult periods of this process, and thanks for reminding not to forget about other important aspects of life. You are heaven sent!

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Abstract

SECURING A SUCCESSFUL FUTURE FOR CHILDREN WITH DEVELOPMENTAL
DISABILITIES IN GHANA AND ZAMBIA: A MIXED-METHODS STUDY OF PARENTAL AND
SERVICE PROVIDER EXPECTATIONS

By Princess-Melissa Washington-Nortey, M.S.

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University

Virginia Commonwealth University

2020

Major Director: Zewelangi Serpell, Ph.D.

Associate Professor of Psychology

Department of Psychology

Studies suggest that parental expectations can influence the developmental trajectory of a growing child. However, the role of parental expectations in the lives of children with disabilities such as intellectual disabilities or autism, and children in Africa in general, to date, has received little attention. Using a cultural psychology framework, the current study examined parental and service provider expectations for children with intellectual disabilities or autism in two African countries: Ghana and Zambia. A mixed-method approach involving the use of concept mapping and quantitative strategies was used. A total of 20 parents and 16 service providers participated in four separate focus groups (one parent and one service provider focus group in each country). During each focus group, participants generated statements

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representing expectations that were sorted into thematic groups and rated on two criteria: importance and likelihood. In phase 2, the generated statements from both focus groups per country, were distributed to a larger group of participants (Ghana N=128 and Zambia N=79) who were asked to rate each statement on importance and likelihood. Results showed that both parents and service providers shared expectations that were congruent with previous literature. However, the contents of these expectation themes were nuanced in a manner that reflected the cultural and historical time period of each region. Additionally, parents and service providers had unique expectations for children that highlight other important aspects of children's lives in these regions of the world. Within each focus group, differences emerged in the perceived importance and likelihood of the thematic clusters. In Ghana, there were significant differences between parents and service providers on the perceived importance and likelihood of some thematic clusters (e.g. independence, vocational opportunities, and educational opportunities). Results are discussed in relation to the cultural salience of particular themes, and implications for future research, intervention and policy development.

Keywords: parental expectations, teacher expectations, health worker expectations, intellectual disabilities, autism spectrum disorders

Securing a Successful Future for Children with Developmental Disabilities in Ghana and Zambia: A Mixed Methods Study of Parental and Service Provider Expectations

Millions of children between 0-14 years old worldwide have disabilities and this number is projected to continue rising (WHO, 2011; Zablotsky et al., 2017). Prevalence rates are highest in low-income countries (WHO, 2011), with 80 percent of people with disabilities living in developing countries (United Nations Development Program, 2018). Reports from the World Health Organization suggest that children with disabilities are at greater risk of enduring poorer life trajectories than their typically developing peers. They are more prone to physical illness, poverty, social isolation, and—as adults—are more likely to be un- or under-employed (WHO, 2011). Ensuring the life-success and adequate meaningful integration of people with developmental disabilities into society is a global challenge, as existing interventions and educational programs across the globe have yielded very limited success. For children with disabilities living in low-resourced countries in Africa, the outlook is even more dire, and little attention has been paid to cultural considerations that may be important for supporting these individuals' successful development.

Recent studies provide preliminary evidence that with adequate familial and societal supports, children with developmental disabilities can live successful and well-integrated lives. Research indicates that important factors that support positive life trajectories for all developing children, include parental expectations and parents' use of material resources to support their children's educational and social success (Hill & Tyson, 2009; Altschul, 2011; Wilder, 2014). Yet few studies probe these positive factors in samples of children with developmental disabilities, and almost none have examined them within an African context. Reports also suggest that intervention protocols transferred across cultural contexts often fail because they do not consider important cultural differences (Carter et al., 2012; Hruschka et al., 2018). As such, addressing the challenge of ensuring the life success of children with disabilities in Africa

requires a comprehensive and cross-national effort, which includes a new perspective and novel approaches that consider culture. The current study seeks to address this knowledge gap and adopts a culturally responsive approach to examining parental expectations for children with disabilities in two African countries: Ghana and Zambia.

Theoretical Framework

Societal norms can influence all aspects of social organization, structure and behavior patterns and at the microlevel, determine what parents desire, expect, or even perceive as normal. Nsamenang (1992) argues that even though a universal/standard pattern may exist, each culture—based on its norms—can craft a unique group of individuals suited for the specific context in which they are developing. He highlights the unique position of most African countries: in danger of losing valued, adaptive customs in the face of the powerful effects of rapid globalization. The effects of rapid globalization trends, he posits, are shaping societal norms such that research methods that probe phenomena from the bottom up are needed to identify specific areas of uniqueness as well as areas that overlap with the global context. Research informed by this perspective aims to maintain useful aspects of global integration, while identifying less optimal aspects as targets for intervention.

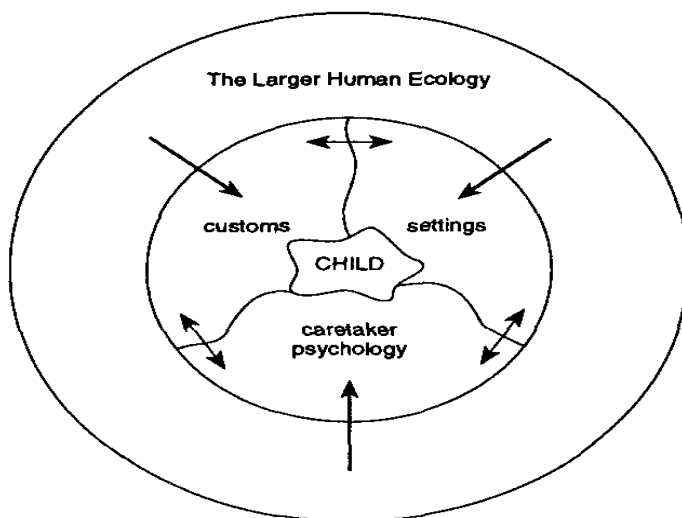
The effects of globalization are witnessed all over Africa. Ghana for instance, a West African country of about 29.76 million people adopted English, the language of its British colonial masters as its official language: requiring each citizen to learn this language in addition to other local languages in the country. Its capital city Accra, home to about 10 million people is the most diverse city in the country (Owusu & Agyei-Mensah, 2011). The ethnic and racial diversity in the capital city is attributed to the availability of increased educational, vocational and social opportunities that exist therein (Ackah & Medvedev, 2010). These factors have and continue to drive residents from all parts of the country to the city.

Similarly, Zambia, a southern African country of about 17.35 million people that was also colonized by the British, adopted English as its official language. Its capital city, Lusaka is the most developed and the most diverse city in the country: attracting locals and expatriates alike (UN World Population Prospects, 2019). In each of these countries, similar educational standards, comparable to global education standards, exist. Both countries are also signatories to several international conventions dictating policy development and practices within them. Yet, in each of these countries, important cultural and contextual factors also impact the implementation and practice of these laws as status. The potential impact of such cultural and contextual norms is discussed later.

A useful framework for investigating cultural contexts of development is Super and Harkness' (1986) developmental niche theory. This theory posits that the development of a child within a microsystem is shaped by the iterative interactions between the child's physical and social setting, the customs of child-care and rearing within that cultural context and the psychology of his/her caretakers. (See Figure 1)

Figure 1

Developmental Niche Model



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The physical and social settings represent environments like schools or farms where activities of daily living take place and how they impact development. The customs of child-care refer to cultural practices that are considered natural or right to people in that community, and the psychology of caretakers refers to the specific beliefs that underlie and give credence to these cultural practices. Therefore, specific beliefs may influence customs or practices pertaining to the care of children with disabilities that can affect their outcomes later. These customs may be evident in the mundane activities and practices of a given society.

Super and colleagues (2011) illustrate how different cultural contexts/environments can influence child development by dictating priorities. The authors suggest that child-rearing practices are guided by an implicit agenda or local curriculum that is prescribed by a desired goal of the cultural context. For families in Western contexts, for example, the goal of school readiness often dictates parent-child interactions (Super et al., 2011). This goal also guides the development of standardized tests such as the Bayley Scale of Infant and Toddler Development, used to track development along this trajectory and predict a child's future success. In contrast, Super et al. (2011) found that parents of children in rural Senegal adhere to a different local curriculum based on different goals—family maintenance and income production—in rearing their children. Specifically, the rural Senegalese curriculum focuses on the socialization of chores, motor development and social rules for good behavior and respectful interaction, none of which were assessed by the Bayley's. Initial developmental tests using an adapted form of the Bayley's showed that these Senegalese children performed more poorly than their Western counterparts but, unlike their overseas peers, their scores did not predict future success (Super et al., 2011). When tested on a new local scale of development that included components of their local curriculum, results predicted growth and development according to the desired goals of the culture and like the Bayley's were correlated with health measures pertaining to hemoglobin levels and physical growth. This study shows that the

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outcome of successful development may differ across cultures. As such, it may not be ideal to simply transfer constructs across cultures. It is important to explore the unique and culturally-defined goals of each context and devise strategies to aide in their attainment. Specific cultural beliefs about the etiology of disabilities in Ghana for instance, can dictate a local curriculum for children with disabilities therein. Indigenous beliefs posit that disabilities are the result of curses from gods or deities meted out on individuals as punishment for offenses committed (Kassah et al., 2012). Consequently, in the past, children with disabilities were ill-treated, isolated from society, and sometimes killed at birth (Botts & Owusu, 2013; Kassah et al., 2012). Moreover, practices that demonstrate a preference for sons in comparison to daughters (Nyarko & Madise, 1999), may also influence the experiences of children in the country irrespective of disability status.

In Zambia, persons with disabilities also face societal discrimination. In the past, they were kept isolated from society and deprived of opportunities to gain important skills that would facilitate their growth and development. Current reports also reveal that Zambia has limited policies for persons with disabilities. Although policies like the 2002 National Policy on Disability that aim to facilitate the integration of persons with disabilities into mainstream society, exist, few specific policies exist. There are currently no policies specifically for people with intellectual disabilities (Mung'omba, 2008), and no policies exist to guide an inclusive education framework in the country (Chirwa, 2011). This contrasts with the prevailing situation in countries like the United States where a myriad of policy frameworks exists to guide practice in almost every area of life.

The Value of Parental Expectations

As suggested by the developmental niche theory, the growth and development of each child is influenced by the interactions among parent or caregiver perceptions, behaviors, and their physical environment. Parents and caregivers often represent the most proximal sphere of

influence to a developing child: providing access to varied structures and opportunities based on their perceptions of appropriateness.

Several constructs have been used to tap into parents' role in the development of their children. Often categorized as "parental involvement", these constructs include: providing educational materials, helping with homework, communicating with teachers about their child's progress, sharing expectations with their child, and many more (see Chowa et al., 2013; Epstein 1995; El Nokali et al., 2010). Of these variables, parental expectations have been shown to be a powerful and consistent predictor of children's academic outcomes at different stages of development and across different generations of children. Attention was first drawn to the uniqueness of this variable through the efforts of Fan and Chen (2001), who in a meta-analysis comprised of 25 studies, showed that—of all the variables considered—parental expectations for children's educational achievement evinced the strongest relationship with academic achievement. This was notable because parental expectations rose above parental involvement variables that theoretically specifically support academic achievement; such as involvement with homework and school, communication about school-related topics, and participation in school-related activities like parent-teacher conferences. More recent meta-analyses have yielded similar conclusions.

In another meta-analysis comprised of 50 studies published between 1985 and 2006, Hill and Tyson (2009) found that of all constructs examined, academic socialization—a construct consisting of parents communicating expectations for education and its value or utility with their children, fostering educational and occupational aspirations, discussing learning strategies with children, linking schoolwork to current events, and preparing for the future—had the strongest positive association with achievement. Similarly, in a meta-synthesis of nine meta-analyses conducted five years later, Wilder (2014) found that parental involvement defined as

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“parental expectations for academic achievement” had the strongest association with academic achievement.

These findings have highlighted the importance of parental expectations, but studies have been largely restricted to families of typically developing children and not specifically for children with developmental disabilities. Emerging literature from the field of developmental disabilities reveal a significantly broader construct of parental expectations with a much wider area of impact. Unlike inquiries in the general parenting literature which focus primarily on parental expectations for academic outcomes, in the area of developmental disabilities, the construct of parental expectations includes expectations about academic, social, functional and vocational achievements. The inclusion of these other domains capture aspects of life that indeed show greater variability within this population of children.

Social expectations include predictions or beliefs pertaining to the development or maintenance of romantic or non-romantic social relationships (Holmes et al., 2016), social acceptance and inclusion (Mutua & Dimitrov, 2001; Papay & Bambara, 2014), and social attainment (Poon, 2013). For instance, Holmes and colleagues (2016) studied parental expectations around their children’s romantic involvement and their communication of sexual health related topics to their children with ASD. One hundred and ninety parents provided information about their 12-18-year-old adolescents with varying severity levels of ASD and intellectual capabilities. Results showed that parents of children with severe levels of ASD had low romantic expectations for their children irrespective of the child’s IQ. Further, for children with below average IQ and ASD, parental romantic expectations mediated the relationship between ASD symptom severity and parents’ communication about sexual behavior and health. Specifically, parents of children with severe ASD were more likely to have lower romantic expectations and subsequently less likely to discuss in sex-related topics with them.

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Some studies examine functional expectations, which in some cases may also be conceptualized as social. These usually pertain to beliefs or expectations about the ability of individuals to live independently (e.g., Magill-Evans et al., 2001) or gain important abilities or skills after treatment. For example, Spahn and colleagues (2003) compared the treatment expectations of parents of children with either cochlear implants or hearing aids. Data from 154 parents of children with hearing aids and 103 parents of children with cochlear implants were analyzed. Their results show that both sets of parents had realistic expectations for treatment outcomes in their children. However, during the early recovery periods, parents of children with cochlear implants had slightly higher expectations compared to parents of children with hearing aids.

Other studies have examined vocational expectations, which capture beliefs about perceived employability whether part or full-time, sheltered or inclusive (Gilson et al., 2018). Examining data from a sample of 673 parents of young adults with intellectual disability, Gilson and colleagues (2018) found that family members' ratings of the importance of part and full-time employment (the value component of expectations) were positively associated with the likelihood of having been recently employed.

Furthermore, like studies in the general parenting literature, some studies examine parents' educational expectations for their children with disabilities. Most of these studies focus on post-secondary educational outcomes (e.g. Chaing et al., 2012) but a few also focus on current educational outcomes (Bush et al., 2018). Chiang and colleagues used data from the National Longitudinal Transition Study 2 (NLTS2), which investigated the experiences of secondary school students in special education settings across the United States, to probe post-secondary expectations for these children. They sampled 830 high school students and found that parental expectations predicted the likelihood of students with autism enrolling in post-secondary education.

Factors Affecting Parental Expectations

As outlined by the bi-directional nature of influences specified in the Super and Harkness (2011) model, parental expectations may be shaped by the norms of childcare, the physical environment and structure it imposes, and even by child-level factors specific to the child in question. Some studies illustrate how this may occur and highlight specific factors that may influence the formation of parents' expectations. The next section reviews such studies under two sub-heading: 1) child-level factors and 2) macro-level cultural influences.

Child-Level Factors.

Child-level factors consist of child characteristics or personal experiences that can influence parents' beliefs about the present or future capabilities of their children with developmental disabilities. Examples identified in extant literature include, child ability, level of functional impairment, symptom severity and participation in general education. Although some of these factors, such as functional impairment and child ability, appear similar and are likely correlated, they are operationally different. Functioning, as operationalized by Barak and colleagues describes the functional skill, and the amount of caregiver assistance needed for the child to perform daily routines (Barak et al., 2017). In contrast, ability captures caregivers' perceptions of a child's capabilities while considering their cognitive and problem-solving capabilities, enjoyment of social interactions, comprehension of emotions, etc (Barak, et al, 2017). In their study examining parents' future expectations for their 6-12-year-old children with cerebral palsy, they found that perceptions of the child's ability predicted both mothers' and fathers' general future expectations. In a qualitative study exploring parents' social expectations of their adolescent children with ASD, Poon (2013) found that the perceived skill set and the level of challenging behavior exhibited by adolescents influenced their parents' expectations of future residential options and employability. For instance, one parent explained how her child's limited attention span decreased his likelihood of being effective and efficient at any

independent task: limiting employment options. Other parents also shared that their children's erratic behavior negatively impacted their confidence about what to expect in varied social settings. Arabsolghar and Elkins (2000) also examined child ability as a predictor of parent and teacher expectations of child's cognitive ability- memory skills—however, they did not obtain significant results. The study was also limited by a failure to operationally define ability or specify the ages of the children in question beyond their primary school status.

In summary, these studies provide preliminary evidence of the impact of child specific factors on parental expectations. Yet, beyond these child-level factors, the environment or culture within which a child develops impacts parental beliefs and expectations about possibilities for development. Although few studies explicitly state this as an aim in their investigations, the results of studies across the globe highlight differences in value systems and demonstrate how existing structures in some of these countries/regions may impact the formation of expectations. The subsequent section reviews findings from different studies that highlight possible differences in value systems across countries and attempts to show systemic factors that might influence these findings.

Macro-Level Cultural Influences.

Cultural norms vary across society. In Western developed countries such as the United States, norms pertaining to individualism/ independence, equal opportunity and inclusion, afforded through mechanisms of education and self-determinism among others are valued highly (Youngelson-Neal, 2014). However, in other parts of the world different sets of social norms may influence expectations. The next section highlights findings from studies that illustrate differences in education, equality and inclusion, and independence through work across diverse cultural contexts.

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The value of educational attainment is witnessed in studies with samples from the United States and other western countries. Ivey (2004) developed a multi-dimensional 20-item parental expectation measure to probe parents' perceptions of the importance and likelihood of their children obtaining specific social, academic and vocational outcomes. The original study explored the phenomenon among 25 parents of children (4-20 years) with autism in the United States. Reflecting the pursuit of American norms, Ivey (2004) found that out of the 20 possible goals/expectations, attending school was the most valued expectation of the sample. Moreover, there was no significant difference between parent ratings of importance and likelihood on this variable. This finding indicated that there was no discrepancy between parents' perception of its importance and the likelihood of their children obtaining this outcome. Similarly, using qualitative interviews, findings from another study suggest that parents of young adults with autism expected their wards to attend college and wanted the necessary supports to be put in place to at colleges to ensure that their children were successful in college (Sosnowy et al., 2018). A study conducted in the United Kingdom also showed that parents there valued educational attainment. Davies and Morgan (2010) found through semi-structured interviews that young adults (17-27 years) with Down syndrome and their parents, did not only desire to attend college but also possessed high expectations for the kind of colleges that they wished to attend. These studies show that individuals from these contexts value educational attainment and strive for the highest levels possible.

In contrast, studies from Asia—where norms of collectivism, social commonality and in some parts, religious beliefs are more highly valued and where disability is stigmatized—reveal different patterns of expectations (Lam & Mackenzie, 2002; Poon et al., 2013). Poon and colleagues (2013) sampled the parents of 105 children with disabilities ranging between 6-18 years and using an adapted form of the same measure used by Ivey (2004), found that unlike findings from the previously reviewed studies, parents of children with autism, intellectual

disability and multiple disabilities in Singapore had lower ratings for educational attainment. Also, unlike their American counterparts, there were significant differences between perceived importance and the likelihood of their children obtaining the desired education. In this sample, being safe from harm, and being happy and satisfied were rated more highly than education.

Western, American values of inclusion and equality are also witnessed in the educational system through policies and strategies that serve a dual purpose of keeping children in schools with their typically developing peers and ensuring their inclusion in society. Law and policies such as the “No Child Left Behind Act”, Individuals with Disabilities Education Act, Response to Intervention, and Least Restrictive Environment strategies ensure the early identification of children at risk and their continued success (Yell et al., 2006). In 2012, Martinez and colleagues investigated parents’ access to information and the impact of their child’s participation in general education on their expectations of post-secondary education. Although parents generally had limited information about educational process beyond high school, their children’s (17-22 year olds) participation in general education classrooms positively predicted their expectations of post-secondary education enrollment (Martinez et al., 2012). Similarly, sampling 150 parents of children with autism in the United Kingdom, Arellano and colleagues identified significant positive correlations between participation in mainstream education and parents’ expectations for their children’s future (Arellano et al., 2017).

On the other hand, studies from Asia suggest that although the idea of inclusive education is becoming increasingly popular, appropriate policies to ensure this are limited, teachers are not fully equipped for this practice, and in some cases inclusive education is not preferred (Elton-Chalcraft et al., 2016; Low et al., 2018; Sharma et al., 2013). Studies outside the school context also demonstrate that opportunities for social participation are limited. Poon (2013) conducted a qualitative study exploring the expectations that parents of children with ASD had regarding post-school outcomes, residential arrangements and community

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participation. Interview findings from the 20 parents in the sample showed they expected limited community participation for their children with ASD because there was limited awareness about and acceptance of children with disabilities in the community. Moreover, some parent responses suggested that informal community efforts aimed at caring for children with disabilities in the past were no longer present: increasing the risk of isolation. Similarly, in Israel, Heiman (2002) used qualitative methods to explore how families with children with disabilities developed resilience and as part of the study, probed future concerns and expectations parents had. The study sampled 32 parents of 7-16 year-old children with intellectual, physical or learning disabilities. Its findings showed that more than half (55%) of the sample had concerns about their children's participation in society. These studies clearly show differences in receptivity to educational and societal inclusion in different cultural contexts.

The value or importance of independence in western cultures is also evident in at least two ways: the importance placed on employment and on independent living. Reports from various studies suggest that American parents of children with disabilities, increasingly desire that their children live independently (Kraemer & Blacher, 2001; Smith, 1981; Sosnowy et al., 2018). While older studies show that children with disabilities, irrespective of their disability type, were largely expected to live with their parents permanently (Smith, 1981), more recent studies, show that independent living is increasingly becoming the expectation (Kraemer & Blacher, 2001; Sosnowy et al., 2018). This trend mirrors expectations for their typically developing peers even though economic challenges are now reversing the trend (Matsudaira, 2016). Moreover, many view employment and financial independence as one of the mechanisms of attaining independence and thus, strongly advocate for the employment of persons with disabilities (Gilson et al., 2018; Sosnowy et al., 2018). In a sample of 673 parents of children with intellectual disability, Gilson and colleagues found that parents expected their children to work

and preferred paid employment options to sheltered, unpaid employment options (Gilson et al., 2018).

Yet again, unlike their American counterparts, reports from Israel and Asia reveal less optimistic patterns. In Poon's (2013) study, none of the 20 parents sampled indicated that independent living was an option. Instead, parents shared that they would continue to maintain full responsibility for their wards, relinquishing it only to other relatives when they are no longer able to support their child. Heiman (2002) also reported that half of the Israeli parent sample expressed concerns about their children's future economic independence, while a third wondered what would happen when they were no longer able to care for their child. In general, these studies also highlight differences in expectations concerning economic and social independence.

Although numerous factors may account for the differences reviewed, many of the studies hint at a lack of or critical need for more resources tailored to meet the needs of children with disabilities and their families (Heiman, 2002; Poon, 2013; Poon et al., 2013, Sharma et al., 2013). Moreover, research suggests that the availability, awareness of and utilization of resources can enhance the developmental growth trajectories of children (Carter et al., 2011).

The Research Gap

Except for two studies, both conducted in Kenya, few studies exist regarding parent expectations of children with disabilities in an African context. Mutua and Dimitrov (2001) reported findings in two separate articles from a research inquiry among Kenyan families with children who had an intellectual disability. Results from the initial study identified community membership, educational attainment and adult responsibilities as constructs of parental expectations among these families. Further, the study identified differences in expectations across gender and symptom severity: males and individuals with milder symptoms had higher

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parental expectations for the future compared to females and individuals with more severe symptoms. The second study examined predictors of school enrollment in the same sample and identified maternal education, parental expectations of social acceptance, beliefs about school appropriateness and, a limited desire to educate children with disabilities as predictors of school enrollment (Mutua & Dimitrov, 2001). The findings from these studies highlight perspectives such as gender differences, which are novel to this social context but may be representative of patterns in other African contexts that merits further examination. These two studies were an important first step at identifying relevant constructs around parent expectations in African contexts but have some limitations.

The use of questionnaires to investigate concepts that have received limited attention, such as parental expectations of children with disabilities, may result in complaint responses that fail to capture nuances within cultures (Kalyanpur & Harry, 2012). Further, while some studies have examined beliefs surrounding disability, investigations about expectations or desires for their children largely do not exist. Furthermore, most studies investigating beliefs are focused on etiology or locus of reasoning surrounding the emergence of disability, and were conducted several decades ago (see Ehlers, 1964; Ewart & Green, 1957). As such, these studies may not adequately capture the perspectives of families in modern African contexts. Existing studies also fail to report the age of the children sampled and the disability type, and do not distinguish between current and future expectations for children with disabilities. Depending on the time period or age of the children in question, expectations may vary, and some questions may not be applicable. Studies also neglect an important dimension of parenting in African societies—the distributed nature of parenting, such that a focus on expectations of parents only, fails to acknowledge the important role of other key stakeholders that may influence expectations for children with disabilities, such as older siblings, grandparents, aunts and uncles, as well as general societal structures and perspectives that may influence parents

perspectives. It is also important to note that the two main studies cited above were conducted in Kenya—a single African country in East Africa. Given the level of diversity in language and culture on the African continent (Moore et al., 2002), it is important to investigate perspectives across countries and regions to enhance ecological validity and generalizability of findings that emerge.

In sum, considering emerging evidence suggesting the importance of parental expectations for children with developmental disabilities and the fact that most children with developmental disabilities reside on the African continent, it is important to consider parental expectations and resource capital of families of children with disabilities in an African context.

The Current Study

This study sought to examine parental and societal perceptions and expectations for children with autism spectrum disorders or intellectual disabilities in two African countries located in two different regions of the continent: in the west—Ghana and in the south—Zambia.

It is important to note is that the term “parent” in this study includes legal guardians such as grandparents, uncles and aunties to reflect the fact that within many sub-Saharan countries child-care is distributed yet the group consists of family members closely acquainted with the care of the child with the disability. A broader community representation—special education teachers and health workers—is included in our participant pool. Two important parts of a developing child with disabilities’ ecosystem are the school and healthcare environments. Therefore, it was also important to glean the perspectives of staff in these settings. Their perspectives are also important because their insight and perspectives are needed to assess potential opportunities for intervention, some of which may be implemented in these same settings. Furthermore, their insight and perspectives will situate parental expectations within the cultural context.

Research Questions

1. What are parental and service provider perceptions and expectations for children with intellectual disabilities or autism?
2. Are there differences between parents and service providers in their perceptions of the importance and the likelihood that these expectations will be manifest?

Method

This study adopted a mixed methods exploratory sequential design (Creswell & Plano Clark, 2011), within a concept mapping methodological framework. In this design, exploratory data is collected using qualitative techniques: focus groups. Data from the qualitative method informed a large survey that was distributed more broadly. This mixed-methods strategy has the advantage of unearthing rich data on less well explored topics and generating enough data to facilitate generalization of the results by com (Creswell & Plano Clark, 2011).

Overview of Concept Mapping

Concept mapping is a theory-based method that uses a collaborative participatory process that enables key stakeholders to be involved in collectively sharing their perspectives on an issue in response to specific prompts. Unlike traditional focus group methodology, it gathers the unfiltered perspectives of key stakeholders and provides a conceptual framework for planning interventions. The method has specific advantages over typical focus group methodology. Although concept mapping, uses a similar qualitative process, to focus group methods, it generates data that can be quantified almost immediately, and that can be used to compare the perspectives of different stakeholder groups (in this study, parents, and service providers) thus eliminating the need for data transcription. It is a mixed-method approach that utilizes a focus group design to generate quantifiable data. The concept mapping process has

seven steps: (1) Preparation—researcher develops the focus of the project by generating a focus group prompt and developing a questionnaire to obtain all relevant demographic information; (2) Identification—researcher identifies and select participants; (3) Generation—participants are brought together to generate ideas or statements; (4) Structuring—statements are sorted and rated by the original participants; (5) Representation—researcher computes maps using the Concepts System® Global MAX™ software (2016) which employs multidimensional scaling and cluster analysis; (6) Interpretation—maps are interpreted for meaning; (7) Utilization—maps are used to plan intervention (Kane & Trochim, 2007). For the purpose of this study, steps 1 through 6 were applicable (i.e., phase 1). However, after these steps were completed with the core focus groups in each country, the statements generated as part of the structuring process (i.e., step 4) were disseminated to a larger sample of participants across stakeholder groups (i.e., phase 2).

Participants

Concept Mapping Phase 1 (Focus Groups)

Study participants comprised two groups of individuals: parents of children with autism or intellectual disability, and service providers such as special education teachers, health workers, and other community stakeholders. The maximum number allowed for each focus group was 12 people.

Concept Mapping Phase 2 (Raters)

A component of the concept mapping process was expanded to obtain additional rating data from the aforementioned groups represented in the focus group in phase 1 of the concept-mapping process. This increased the power of the study to detect an effect and facilitated intergroup comparisons across the different stakeholder groups represented in the focus groups. An a priori power analysis was conducted using the G*Power software (Faul et al.,

2009) to determine the minimum sample size required to detect a medium sized effect, when power of 0.80 was estimated. The medium sized effect estimate was based on studies with typically developing samples showing small to medium sized effects in their results (Gregory & Huan, 2013). Results showed that a sample of size of at least 135 people was required for the current study (if differences were assessed across three groups) and 212 (if differences were assessed across two groups).

Measures

Demographic Questionnaires

Two demographic questionnaires were developed for this study: the parent/guardian questionnaire and the service provider questionnaire. The parent/guardian questionnaire was designed to be completed by the participating caregiver of a child with one of the specified disabilities. It collected demographic information about participants and their children, and preliminary pre-focus group expectations for their children with intellectual disability or autism. The service provider questionnaire collected demographic information, their possible interactions with children with disabilities, and their preliminary pre-focus group expectations for children with intellectual disabilities or autism.

Procedures

Sampling and Recruitment

A combination of convenience and snowball sampling techniques were used to obtain participants for the concept mapping process. Recruitment strategies included the use of paper and email invitations, announcements to specific social/organizational groups, phone calls to referred potential participants, and onsite recruitment. Specifically, the researcher visited organizations or institutions to obtain permission to recruit participants from these sites. Depending on the mission of these organizations/institutions the researcher either recruited

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parents of children with one or both specified developmental disabilities, and/or staff to participate in the study. In addition, during the expanded survey component of the study, children with disabilities were provided with packets that contained copies of the focus group generated statements to be rated by their parents and returned to their respective school administrators.

Eligibility Screening

Screening of potential participants to ascertain eligibility was conducted via phone, email or in-person. Participants were accepted into the parent/guardian focus group, if they met the following eligibility criteria: they had a child diagnosed with either autism or intellectual disability; they were the primary caregiver of the child; and the child spent the majority of their life with them. Participants were accepted into the service provider focus group if they met the following criteria: they were teachers or staff of educational, health or other service provider institutions; they had at least one year of experience in that institution; and as part of their jobs they interfaced regularly with children with the specified disabilities and other children. After screening was completed, participants were informed of the focus group session location, date and time. Participants were reminded of the scheduled focus group one day before each session was held.

Concept Mapping Phase 1 Procedure

The initial phase of the concept mapping process began with a focus group. Two focus groups—one parent group and one service provider group—were conducted in each country. Each group met for a single session (i.e. generation and structuring in the concept mapping protocol). Focus groups took place in the conference rooms of centrally located buildings in the city that were in close proximity to the locations of participants' homes and/or workplaces.

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Prior to initiating each focus group session, participants were consented and requested to complete demographic questionnaires. Next, participants engaged in a brainstorming process in response to specific prompts. After the brainstorming process was complete, they were given a 30-minute break during which refreshments were provided and the researcher made preparations for the remainder of the meeting. On return, participants received packets containing a stack of index cards with one previously generated statement printed on each card, and a questionnaire packet about these statements. Participants grouped the index cards into self-conceptualized thematic piles and rated each statement in terms of importance and likelihood of occurring using a 5-point Likert scale. Participants received their currency equivalent of \$10.00 as compensation at the end of the session. Each session, including the break, lasted approximately 3 hours.

Concept Mapping Phase 2 Procedure

Using statements generated during both focus groups, the researcher created a unique consolidated questionnaire for each country that was distributed more extensively to other parents of children with autism or intellectual disabilities and service providers in the respective cities. Paper surveys, each in an enclosed sealable envelope, were hand-delivered to administrators in institutions and organizations serving children with disabilities. The researcher returned within a week to pick up completed questionnaires. In some cases, the researcher remained in the institution to recruit participants and help them complete the questionnaires onsite per their request (i.e. clarify any aspects that may have been confusing).

Data Analysis Plan

Data derived during phase 1 of the concept mapping process was analyzed using a series of methods: multidimensional scaling and cluster analyses; pattern matching matrices;

and go-zone analyses. A Multivariate Analysis of Variance (MANOVA) was used to analyze data obtained during phase 2.

Multi-dimensional Scaling and Cluster Analyses

Data from the focus groups was analyzed using multi-dimensional scaling and cluster analysis techniques that were computed by the group wisdom concept mapping software (Concept System[®], 2019). Multi-dimensional scaling techniques use each generated statement in the different piles created by the participants as a value entry base upon which a point map is generated. This analytic process yields a stress value which is the degree to which the generated point map fits the original similarity matrix. Although there is no absolute cut-off for stress values, they normally range between 0.1-0.35. Lower stress values indicate a better fit. On the point map, proximally located statements indicate that they were more likely to be grouped together by participants; statements further apart indicate a lower likelihood of being grouped together. Based on the statement distribution in the point map, thematic clusters become evident. The researcher interpreted these clusters by assessing the individual statements that comprise each cluster. Thematic clusters are depicted using visual maps. In addition, using the importance and likelihood ratings provided for each statement, an average importance and likelihood rating was computed for each cluster depicted on the map. These show the relative importance and likelihood of each cluster in comparison to other clusters on the map.

Pattern Matching Matrix

Using the average cluster ratings for each cluster on a map, pattern matrix analysis was conducted to assess potential differences in participants' perceptions of the importance of a particular cluster relative to its likelihood of occurring. For each focus group, average participant

ratings of importance and likelihood specific to each cluster generated in the cluster analysis process were compared and depicted using a pattern matching ladder map.

Go-Zone Analysis

Go-zone analyses were conducted using average importance and likelihood ratings of each rated statement, not the average cluster rating. Each statement was then plotted in one of four quadrants based on the combination of its average importance and likelihood ratings. The four possible quadrants were: 1) most likely and most important; 2) most likely but least important; 3) most important but least likely; and 4) least important and least likely.

Multivariate Analyses of Variance (MANOVA)

For the study phase 2-expanded participant sample survey, MANOVA was used to examine differences between stakeholders on the perceived likelihood and importance of each cluster generated during the focus groups. Separate analyses were conducted for likelihood and importance ratings for each country. The ratings served as dependent variables while participant groups (i.e. parents and service providers) served as the independent variable.

Results

Summary Overview

Concept Mapping

There were four focus groups (Ghana-Parent, Ghana-Service Provider, Zambia-Parent, Zambia-Service Provider) that yielded differing statements that formed unique concept maps within and across countries. For each focus group, reports from the multidimensional scaling procedures with a corresponding point map showing the visual distribution of statements are presented first. Second, hierarchical cluster analyses procedures used to select a specific

cluster solution with its corresponding cluster map are reported. Third, results from pattern matching analysis with a corresponding pattern matching ladder map, showing the relative groupings of these clusters in terms of importance and likelihood are presented. Finally, a Go-zone report with a corresponding map highlighting prospective intervention targets is presented.

Summary of Demographics

Across both countries, the parent sample was mostly female (i.e. Ghana- 100%; Zambia-80%), but majority sex representation differed for service providers per country (i.e. Ghana: 67% male; Zambia 80% female). In Ghana, the mean age and standard deviation of parents was 42.5 years and 4.16 respectively, while the mean and standard deviation for service providers was 38.9 years and 5.57 respectively. In Zambia, 43.1 years and 4.06 were the mean age and standard deviation for parents, while the mean and standard deviation for service providers was 39.7 years and 3.31 respectively. The vast majority of the sample reported a Christian religious affiliation (i.e. Ghana-100%; Zambia-90%) but the level of educational attainment was widely distributed. Among service providers, teaching was the most endorsed profession (i.e. Ghana-44%; Zambia- 96%). All participants were from local ethnic groups in their respective countries (see Table 1 for details). What follows are detailed results for each focus group by country.

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Table 1

Demographic Information for All Focus Groups

		Ghana				Zambia			
		Parent		Service Provider		Parent		Service Provider	
		N	%	N	%	N	%	N	%
Sex	Male	0	--	6	67%	2	20%	1	14%
	Female	10	100%	3	33%	8	80%	6	86%
Ethnicity	Akan	5	50%	7	78%	--			
	Ga-Dangme	2	20%	0		--			
	Ewe	2	20%	1	11%	--			
	Guan	1		1	11%	--			
	Goba					1	10%		
	Lenje					1	10%		
	Bemba					3	30%	1	14%
	Nsenga					2	20%	1	14%
	Chewa					1	10%	2	29%
	Tonga					1	10%	1	14%
	Ngoni					1	10%		
	Missing							2	29%
	Religious Affiliation	Christian	10	100%	9	100%	9	90%	7
Missing		--		--		1	10%	--	
Highest Level of Education	None-Junior high school	3	30%	--	--	2	20%		
	Senior high school/equivalent	3	30%	--	--	5	50%	1	14%
	Vocational/Technical education	3	30%	1	11%	--		2	29%
	Diploma	0	--	1	11%	--		1	14%
	Bachelor's Degree	0	--	3	33%	1	10%	1	14%
	Post-Graduate	1	10%	3	33%	1	10%	1	14%

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Occupation	Professional Accreditation	1	11%	1	10%	1	14%
	Teacher-Gen. Ed.	2	22%			2	29%
	Teacher-Sp. ed	2	22%			4	57%
	Teaching aids	2	22%			--	
	Health workers	1	11%			--	
	Other- community stakeholders/administrators	2	22%			1	14%

Ghana

Qualitative Analysis

Participants. Two focus groups were held in Accra, Ghana: a parent, and a service provider focus group. The parent focus group was composed of 10 individuals, while the service provider focus group was composed of seven individuals. However, two additional service providers participated in the sorting and rating phases of data collection remotely and their data was included as part of the Ghana focus group data. Demographic information about the focus group participants may be found in Table 1.

Parent Focus Group

Multidimensional Scaling and Cluster Analyses. Multidimensional scaling procedures were used to create a point map, shown in Figure 2, after 16 iterations. The stress value, a fit index produced by the concept mapping software, was 0.1998.

Figure 2

Point Map for the Parent Focus Group-Ghana



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Hierarchical cluster analysis techniques were used to generate multiple cluster solutions. To select the appropriate cluster solution, several potential cluster solutions were selected for examination by comparison. Each potential solution was examined first by carefully inspecting the proposed labels and the items within each cluster. When the examination revealed that the clusters might contain multiple themes within them, alternative cluster solutions were examined. In some cases, the alternative cluster solutions helped clarify these themes by grouping them as unique clusters. However, if items did not migrate when alternative solutions were examined, the initial cluster was maintained but the label was adjusted to reflect the broader theme suggested by all items within the cluster. The final cluster solution was cross-checked with another researcher as a verification check.

For this focus group, a five-cluster solution was selected based on the conceptual clarity of contents in each cluster, fit with the data and the number of times items within that cluster that were likely to be grouped together by different participants (see. Fig. 3). These clusters were labelled: *independence*, *acceptance and inclusion*, *education*, *access to government resources*, and *healthcare*. The clusters are described as follows: the *independence* cluster contained statements about self-care, autonomy, and choice; the *acceptance and inclusion* cluster contained statements about societal and familial acceptance, and fair treatment; the *education* cluster contained statements about educational access, experience and outcomes; *access to government resources* contained a statement requesting access to government grants for persons with disabilities; and *healthcare* contained statements about healthcare experiences and access for people with disabilities. Cluster titles with their average ratings on importance and likelihood are presented in table 2. A table with the contents of each cluster is also presented in the appendix.

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Figure 3

Cluster Map for the Parent Focus Group-Ghana

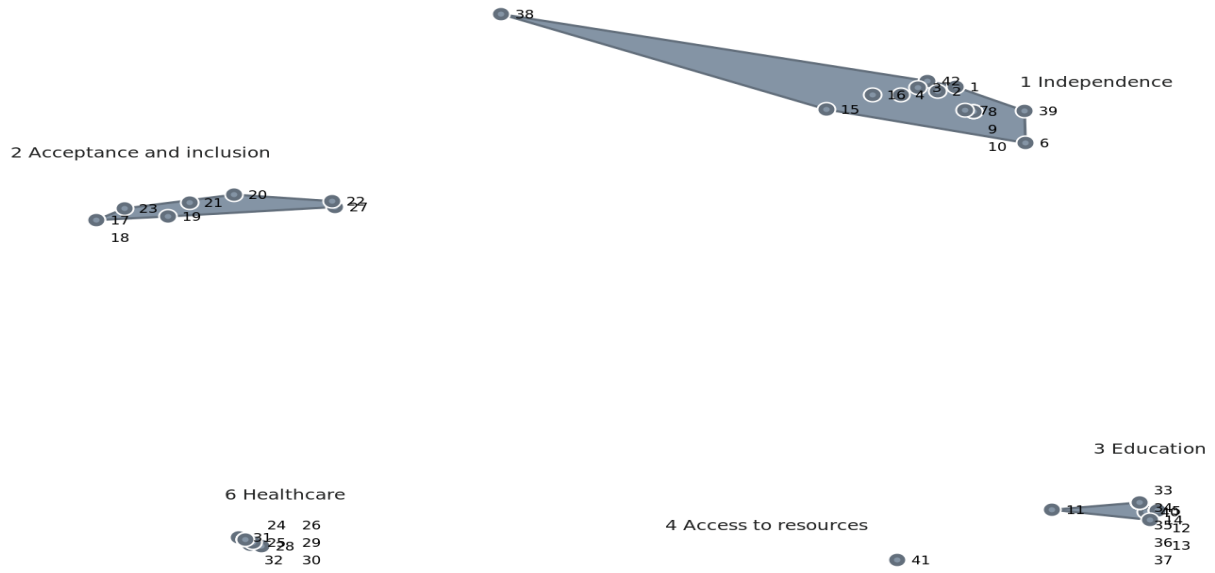


Table 2

Cluster Titles with Average Ratings on Importance and Likelihood

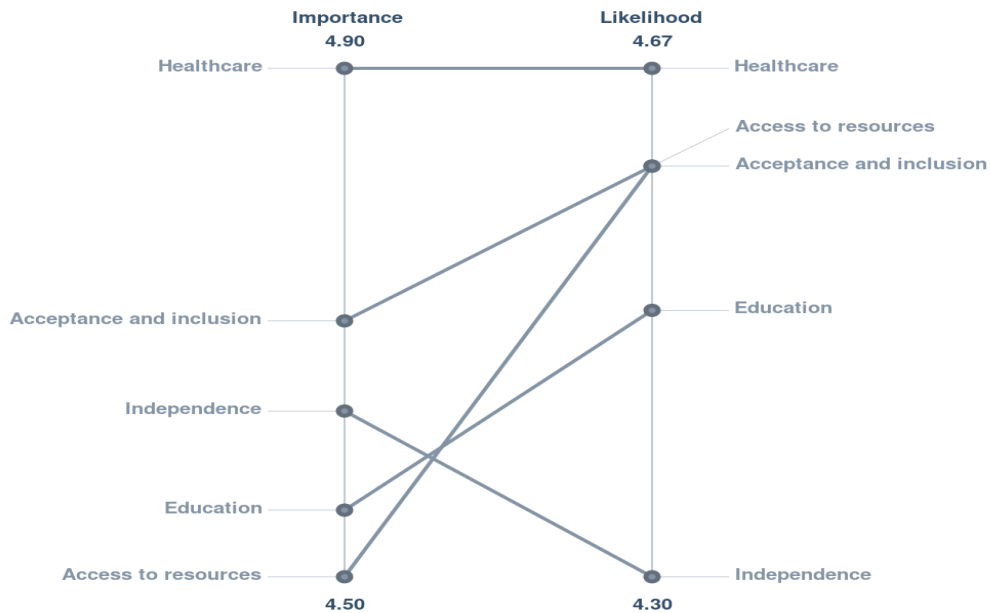
	Parent Label (<i>M</i>-importance; <i>M</i>-likelihood)	Service Provider Label (<i>M</i>-importance; <i>M</i>-likelihood)
Ghana	Healthcare (4.90 ; 4.67)	Independence (4.63 ; 4.14)
	Acceptance and inclusion (4.70 ; 4.60)	Government policy and involvement (4.52 ; 3.70)
	Independence (4.63 ; 4.30)	Involvement of religious institutions (4.52 ; 4.15)
	Education (4.55 ; 4.50)	Vocational opportunities and protections (4.44 ; 3.77)
	Access to (Government) resources (4.50 ; 4.60)	Educational policy and practice (4.42 ; 3.96)
		Professional and caregiver training (4.41 ; 3.84)
		Equal social rights and opportunities (4.40 ; 3.68)
		Educational rights and opportunities (4.39 ; 3.69)
		Love and acceptance (4.29 ; 3.83)

Pattern Matching Analysis. Average importance and likelihood cluster ratings were compared against each other to create a pattern matching matrix. Average importance ratings across all clusters, were generally high (i.e., 4.50-4.90). Comparatively, parents rated *healthcare*, as having the highest importance. It was followed by *acceptance and inclusion*, *independence*, *education*, and lastly, *access to resources*. Average likelihood ratings were slightly lower than importance ratings (i.e., 4.30-4.67). However, the *healthcare* cluster received the highest rating compared to the other clusters. *Access to government resources* was rated as the second most likely cluster, and subsequently, *acceptance and inclusion*, *education*, and

independence. The correlation between average importance and likelihood ratings was moderate (i.e., 0.4). The corresponding pattern matching ladder map is shown in Figure 4.

Figure 4

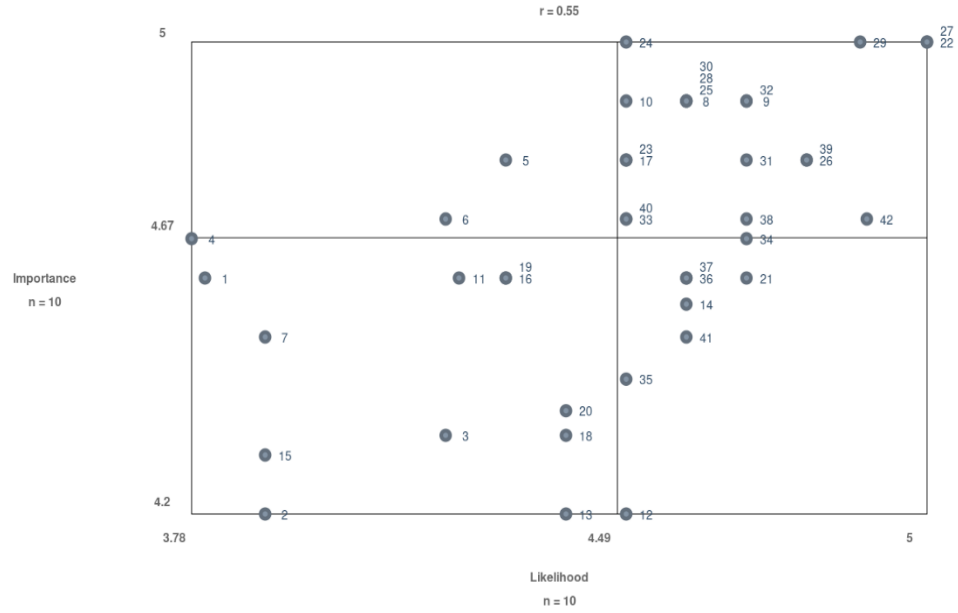
Pattern Matching Ladder Map for the Parent Focus Group: Ghana



Go-Zone Analyses. A bivariate plot shows that most statements were split between the important and likely quadrant (i.e., top right) or the not important and not likely quadrant (i.e. bottom left). The specific statements in the important and likely quadrant are presented in table 3 as they represent the best targets for intervention. The full plot is shown in Figure 5.

Figure 5

Go-Zone Analysis for the Parent Focus Group: Ghana



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Table 3

Recommended Targets for Intervention: Ghana

Focus Group	Cluster Name	Statement #	Statement
PARENTS	Independence	8	To learn to brush their teeth.
		9	To learn to wear their own shoes.
		10	To learn to dress themselves.
		38	To come to know God for themselves.
		39	To be potty trained.
		42	To be able to decide between what is right and what is wrong.
	Acceptance and inclusion	17	To be accepted in society for who they are.
		23	For their specific conditions to be well understood by society.
		27	To be treated with love by their parents.
		22	To be loved by their parents.
		40	For teachers to adapt to the needs of children with special needs.
		33	For nursery and primary school teachers to know where to refer children with disabilities.
	Healthcare	24	To be identified early in the hospitals by the doctors.
		30	To receive immediate treatment (i.e., they should not have to wait in line).
		25	For health practitioners to communicate the conditions to parents as early as possible.
		28	To be given medication that works.
		32	For health practitioners to know where to refer children with disabilities.
		31	For health practitioners to know how to identify children with disabilities.
		29	For health professionals to treat them with patience
		26	To be given special attention or treatment in the hospitals.
	Education	34	To have access to inclusive education.

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SERVICE PROVIDERS

Equal social rights	8	For society to see them as humans (not second-class citizens). That children/persons with special needs will not be abused by security personnel.
	43	
Love and acceptance	19	That they will be loved by parents and relatives.
Vocational opportunities and protections	30	That they will be paid fairly in the workplace.
Educational rights and opportunities	17	They will have access to appropriate equipment, facilities, and resources. They will have access to an appropriate environment for learning.
	16	
Educational policy and practice	15	That their teachers will desire to bring out the best in them. That their teachers will be well-equipped to work with them.
	14	
Independence	2	To know what they need and have that need be respected once it is in their best interest. To be able to communicate their wishes to others. To be independent.
	3	
	1	
Professional and caregiver training	38	Their caregivers will be educated about their dietary needs/restrictions based on their specific disabilities and health needs. That their parents and other relatives will be trained to effectively handle them.
	39	

EXPECTATIONS FOR CHILDREN WITH DISABILITIES

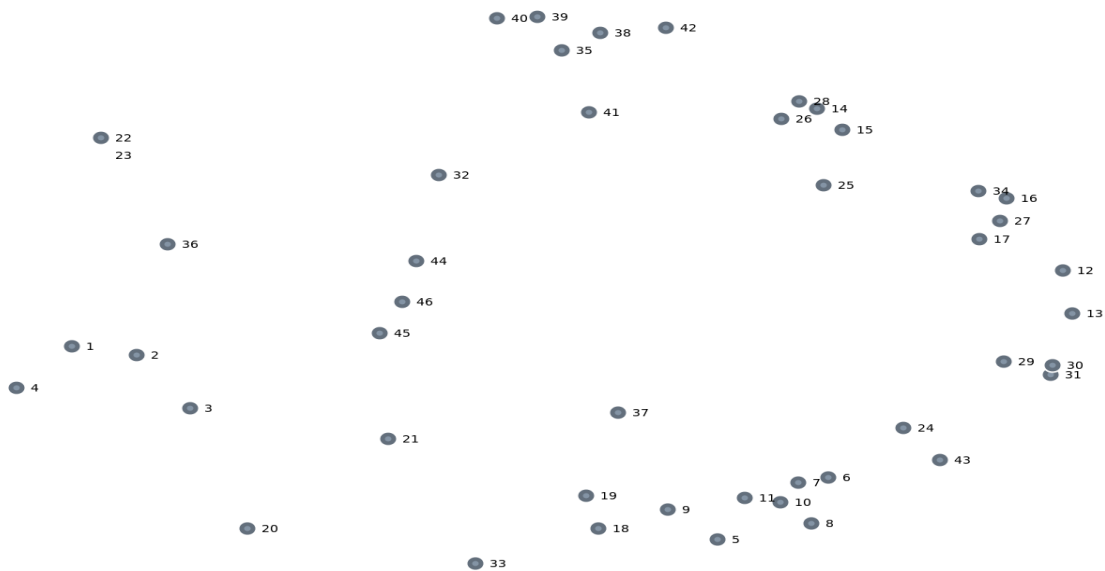
Involvement of religious institutions	35	Health professionals will be trained specifically to work with children with special needs.
	44	Religious institutions will be involved in raising awareness about the needs of these children.
	45	Religious institutions will welcome children with special needs.

Service Provider Focus Group

Multidimensional Scaling and Cluster Analyses. The point map for this focus group was produced using multidimensional scaling procedures after 9 iterations. Although the stress value was higher than the previous maps at 0.2903, it was still below the recommended cut-off of 0.365 (Kane & Trochim, 2007). The corresponding point map is shown in Figure 6.

Figure 6

Point Map for the Service Provider Focus Group: Ghana



Similar procedures involving the examination of potential cluster solutions for conceptual clarity, fit with the data, likelihood of the same items being grouped by different participants, and a final verification check with another researcher were used to select a cluster solution for this focus group.

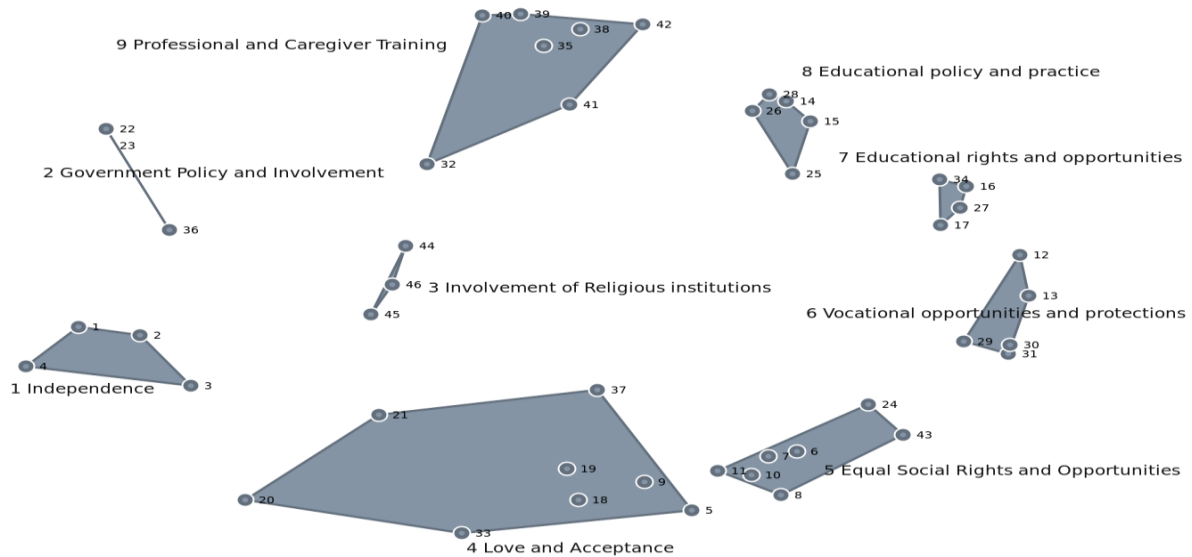
After discussions, a 9-cluster solution was selected (see. Figure 7). These 9 clusters were labelled: *independence, love and acceptance, equal social rights and opportunities, vocational rights and protections, educational rights and opportunities, educational policy and*

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practice, government policy and involvement, involvement of religious institutions, and professional and caregiver training. These themes are described: *independence* contained statements about choice and autonomy; *love and acceptance* contained statements about personal, familial, and societal love, acceptance and fair treatment; *equal social rights and opportunities* contained more specific statements about societal access and protection from discrimination; *educational policy and practice* contained statements about the educational context to which children would be exposed; *educational rights and opportunities* contained statements about educational access; *vocational opportunities and protections* contained statements about vocational training and work place experiences; *government policy and involvement* contained statements about the development of policies and allocation of funds to cater to their development; *involvement of religious institutions* contained expectations about children's involvement in religious institutions and the role of these institutions; and *professional and caregiver training* contained statements about awareness creation, as well as the skill set of parents and professionals who care for these children. See table 2 for the average importance and likelihood ratings for each of these clusters. The appendices also contain a table that lists the contents of each cluster.

Figure 7

Cluster Map for the Service Provider Focus Group-Ghana

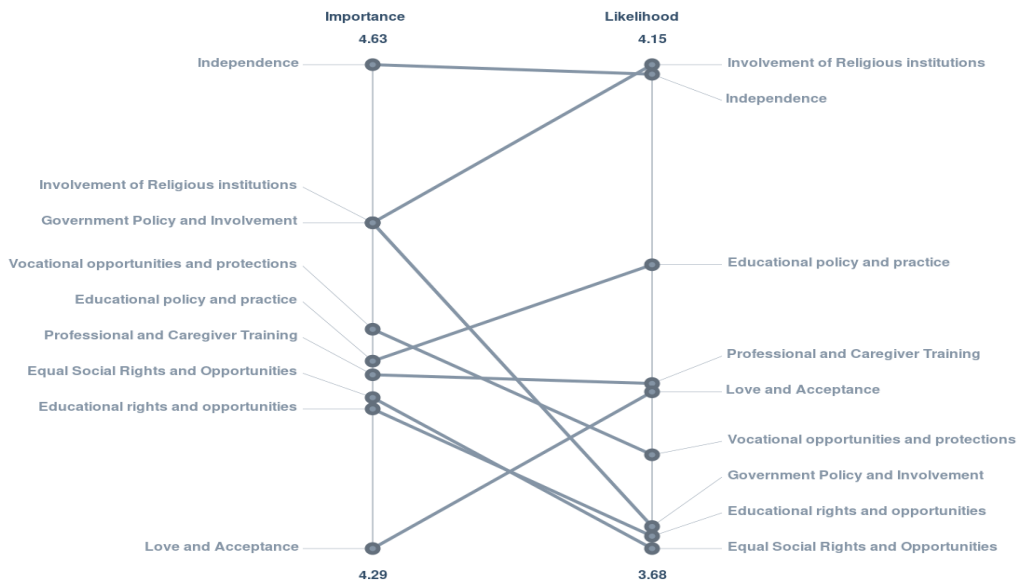


Pattern Matching Analysis. Average ratings of importance and likelihood for each cluster were compared against each other to create a pattern matching matrix. The average importance ratings across all clusters were generally high (i.e., 4.29-4.63). In comparison to other clusters on the importance rating, *independence* was rated highest, followed by *involvement of religious institutions*, *government policy and involvement*, *vocational opportunities and protections*, *educational policy and practice*, *professional and caregiver training*, *equal social rights and opportunities*, and *educational rights and opportunities* respectively. Average likelihood ratings, which were relatively lower than average importance ratings (i.e., 3.63-4.15), evidenced *involvement of religious institutions* as the most likely followed by *independence*, *educational policy and practice*, *professional and caregiver training*, *love and acceptance*, *vocational opportunities and protections*, *government policy and involvement*, *educational rights and opportunities*, and *equal social rights and opportunities*. The

correlation between average importance and likelihood ratings was high (i.e., 0.58). Figure 8 illustrates this information in a pattern matching ladder map.

Figure 8

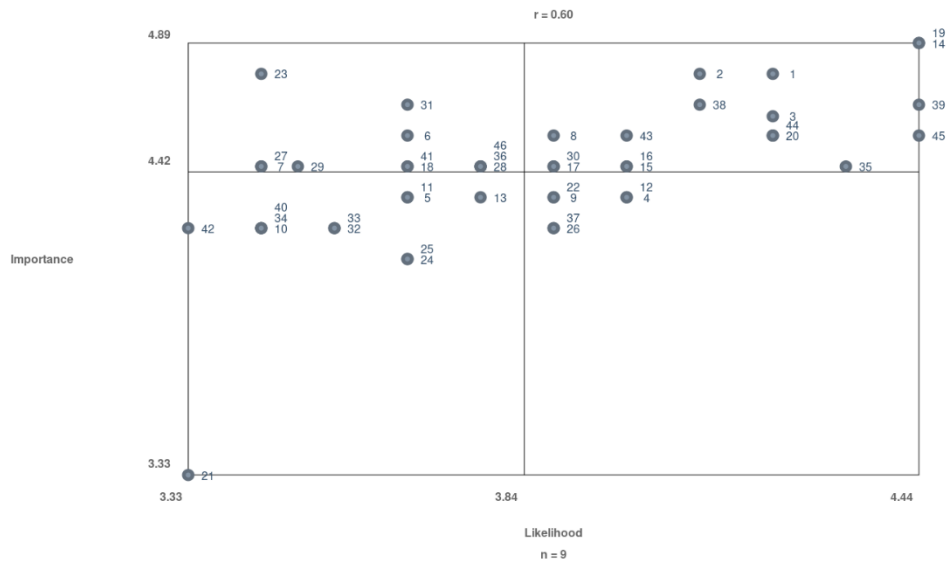
Pattern Matching Ladder Map for the Service Provider Focus Group: Ghana



Go-Zone Analysis. In this bivariate plot, it is clear that most of the statements were deemed as fair to very important since most were close to or above the midpoint. However, it is also clear that service providers strongly perceived statement number 21 (i.e., *that children with disabilities be allowed to start families of their own*) as the least important and least likely). This is an important finding given that, in their focus groups, many parents desired this for their children with disabilities and rated it fairly high on the importance and likelihood scales. Table 3 presents a list of statements that fell into the top right quadrant, signifying that they were perceived as both important and likely, and may therefore serve as excellent targets for intervention. The full go-zone plot is displayed in Figure 9.

Figure 9

Go-Zone Analysis for the Service Provider Focus Group: Ghana



Quantitative Analysis

In study phase 2, surveys were created using the statements generated by both the parent and service-provider focus groups, and participants were asked to rate the perceived importance and likelihood of each of the statements on a 5-point Likert scale. These surveys were distributed to a larger group of participants described below. Subscales representing the clusters that emerged from the parent and service provider focus group analyses were created. However, given the variation in the clusters from the parent and service provider focus groups—even when cluster themes overlapped; in the quantitative analysis, data originating from the

parent focus group was treated as separate from the data originating from the service provider group.

Parent Demographic Information. Fifty-one parents completed the questions. Twenty-four parents (47.1%) were female, 21 (41.2%) were male, and 6 (11.8%) did not indicate their sex. All parents but one were Ghanaian. Forty-three parents (84.3%) were Christian, six (11.8%) were Muslim, one (2.0%) endorsed an “other religious category, and one (2.0%), endorsed no religious affiliation. The most frequently endorsed educational attainment option was a post-graduate degree with 16 endorsements (31.4%). Additional demographic information is presented in table 4.

Service Provider Demographic Information. Seventy-seven providers composed of special education teachers (n=17), special education teaching aids (22), and health workers (n=38). Fifty-three (68.8%) were female and twenty-three (29.9%) were male. All service providers were Ghanaian, there were sixty-three (83.1%) Christians, seven (9.1%) Muslims, one person (1.3%) of an “other religious affiliation, and one person (1.3%) who endorsed no religious affiliation. All service providers were Ghanaian (100%), and a bachelor’s degree was the modal educational attainment category with 32 (41.5%) service providers endorsing this category. Additional demographic information is provided in table 4.

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Table 4

Additional Demographic Information for Survey Participants: Ghana

	Parents				Special Ed. teachers				Teaching aids				Health workers			
	N	%	M	SD	N	%	M	SD	N	%	M	SD	N	%	M	SD
Age			41.92	8.03			36.78	9.67			27.35	8.71			28.69	4.96
Education																
High School	6	11.8					--			1	4.5					
Diploma or less																
Senior High School diploma	7	13.7					--			10	45.5			1	2.6	
Vocational/Technical training	5	9.8					--			2	9.1					
Teacher training/nursing diploma	2	3.9					--			1	4.5			11	28.9	
HND/diploma	4	7.8					--			2	9.1			7	18.4	
Bachelor's degree	7	13.7					14	82.4		6	27.3			12	31.6	
Postgraduate	16	31.4					3	17.6						6	15.8	
Professional	2	3.9					--							1	2.6	
Missing	1	1.9					--									
Total	51	100.0					17	100.0		22	100.0			38	100.0	

Preliminary Analysis. Data were aggregated based on the 5-cluster and 9-cluster themes that emerged from the parent and service provider focus group. Thus, there were five subscales (clusters) each for the importance and likelihood ratings from the survey developed using parent focus group data, and nine subscales (clusters) each for the importance and likelihood ratings from the survey developed using service provider focus group data.

MANOVAs were used to probe mean differences in each set of clusters by type of service provider to determine whether service providers were similar enough to be grouped as one. The MANOVA probing differences in the set of *importance* clusters from the parent focus group-based survey by service providers (i.e., special education teachers, teaching aids, and health workers) was not significant (Wilks' $\Lambda = .732$, $F_{(10,56)} = .950$, $p = n.s.$, partial $\eta^2 = .144$). Similarly, the MANOVA probing differences in the corresponding set of parent focus group *likelihood* clusters by service providers was also not significant (Wilks' $\Lambda = .599$, $F_{(10,42)} = 1.29$, $p = n.s.$, partial $\eta^2 = .226$). Therefore, in the main analysis based on the parent focus group survey, all service providers were treated as one group and compared with parents.

The MANOVA examining differences in the service-provider groups on the *importance* ratings of clusters was significant (Wilks' $\Lambda = .418$, $F_{(18,62)} = 1.89$, $p = 0.034$, partial $\eta^2 = .354$). Indicating that there were differences in responses between the service providers. An examination of mean values for each aggregate cluster showed that for almost every cluster, health workers evidenced lower means in comparison to both special education teachers and teaching aids. A closer examination using post-hoc analysis showed that there was a significant difference between special education teachers and health workers on the importance cluster on *government policy*. However, the MANOVA probing differences in the service provider groups' likelihood ratings of the clusters was not significant (Wilks' $\Lambda = .624$, $F_{(18,76)} = 1.12$, $p = n.s.$, partial $\eta^2 = .210$). As such, in the main analysis service providers were not treated as one group, and instead were examined as two separate groups: teachers and health workers.

Main Analysis. Four separate one-way MANOVAs were conducted. For each analysis, participant group (i.e., parent vs service provider) served as the independent variable. The dependent variables were mean ratings of importance and mean ratings of likelihood of statements comprising the parent focus group's clusters and the service provider focus group's clusters.

Parent Focus Group-based Survey. MANOVAs were used to probe differences in each set of clusters. The one-way MANOVA examining mean differences in the importance ratings of clusters by participant type (i.e. parents vs service providers) was significant (Wilks' $\Lambda = .788$ $F_{(5, 51)} = 2.75$, $p = .028$, partial $\eta^2 = .212$). Similarly, the one-way MANOVA examining mean differences in the likelihood ratings of clusters by participant type was also significant (Wilks' $\Lambda = .738$ $F_{(5, 51)} = 3.62$, $p = .007$, partial $\eta^2 = .262$). Means and standard deviations, as well tests of between-subjects effects results are presented in tables 5 and 6 respectively. Results from the between-subjects tests show a significant difference between parents and service providers only on the perceived importance of *independence*. For the likelihood ratings; there were significant differences between parents and service providers on the *independence*, *education*, and *acceptance and inclusion* clusters. For each of these, parents evidenced the higher mean score.

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Table 5

Means and Standard Deviations for Importance and Likelihood Clusters in the Parent Focus Group-Based Survey

Aggregate Cluster names		Importance		Likelihood	
		M	SD.	M	SD
Independence	parent	60.45	4.758	58.574	6.436
	service providers	55.94	4.935	50.48	9.17
	Total	57.68	5.309	54.46	8.87
Education	parent	49.73	5.40	47.43	6.27
	service providers	48.03	4.630	43.59	7.39
	Total	48.68	4.965	45.47	7.08
Healthcare	parent	38.27	3.019	35.79	4.35
	service providers	37.17	2.813	34.86	4.27
	Total	37.60	2.915	35.32	4.29
Acceptance and inclusion	parent	33.73	2.492	31.93	3.44
	service providers	33.34	2.235	27.90	5.35
	Total	33.49	2.323	29.88	4.91
Access to government funds	parent	4.64	.66	3.68	1.19
	service providers	4.63	.59	3.66	1.01
	Total	4.63	.62	3.67	1.09

Table 6

MANOVA Examining Importance and Likelihood Clusters by Participant Type in the Parent Focus Group-Based Survey

Cluster	Predictor	Criterion	df	F	Partial η^2	
Importance	Participant type	Independence	1	11.60*	.174	
		Education	1	1.60	.028	
		Healthcare	1	1.96	.034	
		Acceptance and inclusion	1	.37	.007	
		Access of government funds	1	.00	.000	
	Likelihood	Participant type	Independence	55		
			Education	55		
			Healthcare	55		
			Acceptance and inclusion	55		
			Access of government funds	55		
			Independence	1	14.76*	.212
Education	1	4.46*	.075			
Healthcare	1	.66	.012			
Acceptance and inclusion	1	11.35*	.171			
Access of government funds	1	.006	.00			

* $p < .05$

Service Provider Focus Group-based Survey. The one-way MANOVA used to examine mean differences in the set of importance clusters from the service provider-based survey by participant type (i.e., parents, teachers and health workers) was significant (Wilks'

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$\Lambda=.528$, $F_{(18,124)} = 2.60$, $p=.001$, partial $\eta^2=.274$). Likewise, the MANOVA examining mean differences in the set of corresponding likelihood clusters was also significant (Wilks' $\Lambda=.608$, $F_{(18,150)} = 2.351$, $p=.003$, partial $\eta^2=.220$). Means and Standard Deviations as well as results from between subjects test are shown in tables 7 and 8 respectively. Results from these showed that on the importance clusters, significant differences between group means emerged on the following clusters: *independence*, *equal social rights and opportunities*, *vocational opportunities*, and *educational opportunities*. However, on the likelihood clusters, significant group means emerged on the following clusters: *independence*, *love and acceptance*, *equal social rights*, *vocational opportunities*, *educational opportunities*, and *educational policies and practice*.

Follow-up Bonferroni post-hoc analysis on the importance clusters showed that, parents had significantly higher means than health workers on the *independence* cluster, while teachers had significantly higher means than health workers on the *vocational opportunities* cluster. However, follow-up post-hoc analysis on the likelihood clusters showed that on the clusters representing *independence*, *love and acceptance*, *equal social rights*, *vocational opportunities*, *educational opportunities*, and *educational policy*, parents had significantly higher likelihood means than teachers. Parents also evidenced significantly higher mean likelihood ratings than health workers on *independence*, *love and acceptance*, *equal social rights*, *vocational opportunities*, *educational opportunities*, and *educational policy clusters*. Therefore, all differences on the likelihood clusters were between either parents and teachers or parents and health workers but never between teachers and health workers (i.e., service personnel).

EXPECTATIONS FOR CHILDREN WITH DISABILITIES

Table 7

Means and Standard Deviations for Importance and Likelihood Clusters in Service Provider-Based Survey Grouped

<u>Aggregate Cluster name</u>		Importance		Likelihood	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Independence	Parents	18.90	1.680	18.05	2.877
	Sp. Ed teachers	17.74	1.910	15.38	3.843
	Health workers	16.91	1.411	16.28	2.75
	Total	17.97	1.856	16.79	3.31
Government policies	Parents	13.84	1.440	12.57	2.48
	SpEd teachers	14.37	1.012	11.63	2.89
	Health workers	13.35	1.43	11.08	2.87
	Total	13.82	1.38	11.87	2.76
Religious involvement	Parents	13.90	2.34	13.00	2.686
	SpEd teachers	13.74	1.79	11.71	3.72
	Health workers	13.43	1.65	12.24	2.63
	Total	13.71	1.99	12.42	3.00
Love and acceptance	Parents	37.84	2.22	36.84	3.77
	SpEd teachers	36.84	2.14	32.04	6.40
	Health workers	36.17	2.87	31.72	5.22
	Total	37.05	2.50	34.01	5.56
Equal social rights and opportunities	Parents	33.58	2.13	31.68	4.53
	SpEd teachers	33.32	2.36	26.67	6.39
	Health workers	31.87	3.43	26.56	5.601
	Total	32.97	2.73	28.79	5.91
Vocational opportunities	Parents	23.90	2.02	22.73	3.21
	SpEd teachers	24.63	.60	19.33	4.90
	Health workers	23.00	2.32	18.88	3.82
	Total	23.80	2.00	20.66	4.28
Educational opportunities	Parents	18.94	1.44	18.27	2.26
	SpEd teachers	19.00	1.29	15.33	4.11
	Health workers	17.91	1.70	15.64	3.70
	Total	18.63	1.55	16.69	3.54

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<u>Aggregate Cluster name</u>		<u>Importance</u>		<u>Likelihood</u>	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Educational policy	Parents	23.94	1.90	23.22	2.86
	SpEd teachers	23.84	1.57	19.79	4.46
	Health workers	22.65	2.40	19.60	3.81
	Total	23.51	2.06	21.21	4.00
Parent and professional training	Parents	32.9355	2.84	30.97	4.58
	SpEd teachers	33.4211	1.84	28.38	5.79
	Health workers	31.7826	2.84	28.20	4.67
	Total	32.6986	2.67	29.44	5.09

Table 8

MANOVA Examining Importance and Likelihood Clusters by Participant Type in the Service Provider Focus Group-based Survey

<u>Cluster</u>	<u>Predictor</u>	<u>Criterion</u>	<u>df</u>	<u>F</u>	<u>Partial η^2</u>
<u>Importance</u>	Part. Type	Independence	2	9.68**	.217
		Government policy	2	3.02	.079
		Religious involvement	2	.36	.010
		Love and acceptance	2	3.21	.084
		Equal social rights and opportunities	2	2.95	.078
		Vocational opportunities	2	3.99*	.102
		Educational opportunities	2	3.89*	.100
		Educational policy	2	3.08	.081
		Parent and professional training	2	2.25	.061
		Independence	70		
		Government policy	70		
		Religious involvement	70		
		Love and acceptance	70		
		Equal social rights and opportunities	70		
		Vocational opportunities	70		
		Educational opportunities	70		
		Educational policy	70		
		Parent and professional training	70		

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Cluster	Predictor	Criterion	df	F	Partial η^2
Likelihood	Part. Type	Independence	2	5.76*	.122
		Government policy	2	2.38	.054
		Religious involvement	2	1.42	.033
		Love and acceptance	2	10.23**	.198
		Equal social rights and opportunities	2	9.24**	.182
		Vocational opportunities	2	9.11**	.180
		Educational opportunities	2	7.57*	.154
		Educational policy	2	9.88**	.192
		Parent and professional training	2	3.09	0.69
		Independence	83		
		Government policy	83		
		Religious involvement	83		
		Love and acceptance	83		
		Equal social rights and opportunities	83		
		Vocational opportunities	83		
		Educational opportunities	83		
		Educational policy	83		
		Parent and professional training	83		

** $p < .001$, * $p < .05$,

Zambia

Qualitative Analysis

Participants. Two focus groups were held in Lusaka, Zambia: a parent, and a service provider focus group. The parent focus group was composed of 10 individuals, while the service provider focus group was composed of seven individuals. Demographic information about the focus group participants can be found in Table 1.

Parent Focus Group

Multidimensional Scaling and Cluster Analyses. The multidimensional scaling procedures yielded a point map after 8 iterations with a stress value of 0.2195 which was below

the cut-off of 0.365 (Kane & Trochim, 2007). Figure 10 shows the point map depicting the distribution of generated statements.

Figure 10

Point Map for the Parent Focus Group: Zambia



Using hierarchical cluster analysis, several potential cluster solutions were generated. The item statements and labels (suggested by participants) within each cluster were examined for fit with the data, thematic clarity, and number of times participants grouped those specific items together. In the event that a cluster solution seemed to contain other themes within the specified clusters an alternative cluster solution was considered. Alternative solutions were chosen if they showed cleaner thematic representations. Otherwise, the original cluster solution was selected, and the label changed to reflect the broader theme. The cluster solution was discussed with another researcher as a verification check.

A 7-cluster solution was selected for this focus group and is displayed in Figure 11. The clusters were labelled as follows: *independence*; *social skills*; *public awareness and sensitization*; *protection from abuse*; *government assistance*; *training*; and *policy and practice within school contexts*. The cluster of *independence* was composed of statements related to self-care, while public awareness and sensitization contained statements about societal

comprehension of disabilities and protection from discrimination. *Policy and practices within school contexts* was made up of statements pertaining to the kind of environment that children would encounter in school as well as the outcomes they would achieve; *child training* described expectations for contexts where children would receive practical training, *protection from abuse* contained statements about physical and sexual safety of children; *social skills* contain specific statements about the attainment of social skills; and *government assistance* contained expectations about support needed from governments to promote the optimal development of children. Table 9. Lists the cluster titles with their respective average ratings on importance and likelihood. A table with all the contents of each cluster can be found in the appendices.

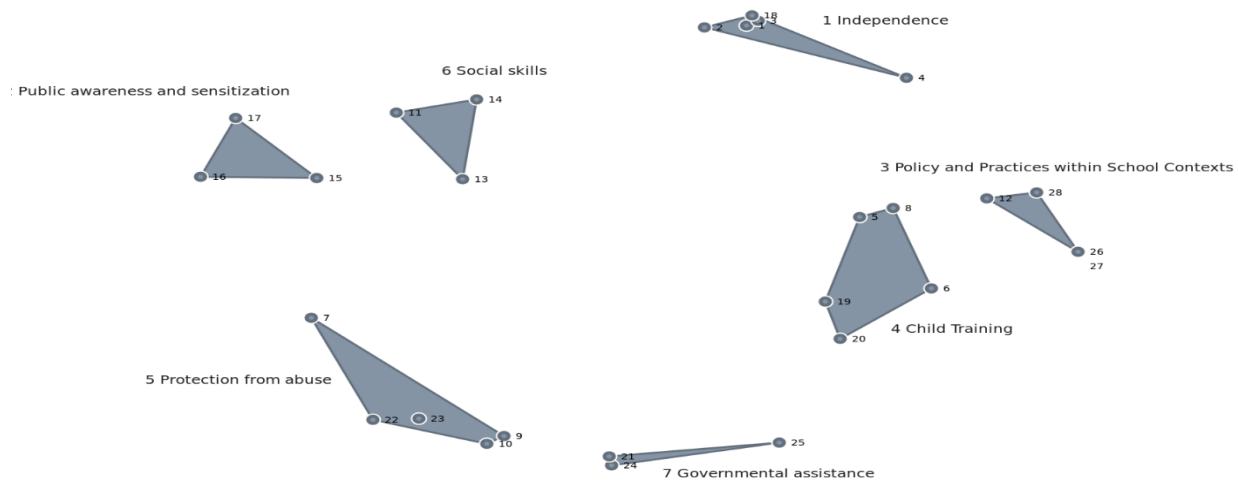
Table 9

Cluster Titles with Average Ratings on Importance and Likelihood:Zambia

Parent Label (importance; likelihood)	Service Provider Label (importance; likelihood)
Public and awareness and sensitization (4.93 ; 4.37)	Health and gender-based violence awareness (4.71 ; 3.86)
Government assistance (4.80 ;4.33)	Parental involvement (4.61 ; 3.93)
Child Training (4.77 ; 4.33)	Personal and public awareness (4.57 ; 3.64)
Independence (4.74 ; 4.28)	Educational opportunities (4.40 ; 3.52)
Policy and practice within school contexts (4.69 ; 4.56)	Equal social rights and opportunities (4.37 ;3.45)
Social skills (4.69 ;4.33)	Independence (4.19 ; 3.50)
Protection from abuse (4.31 ; 4.14)	

Figure 11

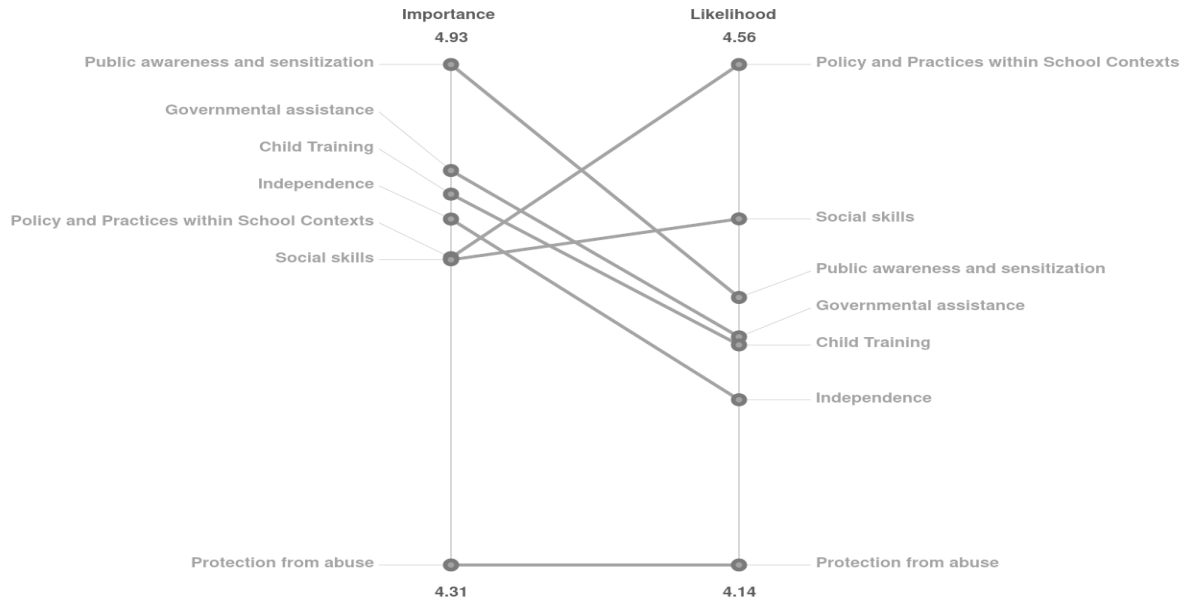
Cluster Map for the Parent Focus Group-Zambia



Pattern Matching Analysis. Average cluster ratings for each cluster were used to create a pattern matching matrix. In general, average importance ratings across all clusters, were high (i.e., 4.31-4.93). Comparatively, parents rated *public awareness and sensitization* as the most important cluster followed by *government assistance*, *training*, *self-reliance*, *practices within school contexts*, *social skills*, and *protection from abuse* in sequential order. Average parent ratings for the likelihood clusters were also high (i.e., 4.14-4.56) though generally lower than importance ratings. Here, *practices within school contexts* were ranked highest, followed by *social skills*, *public awareness and sensitization*, *government assistance*, *training*, *self-reliance* and *protection from abuse*. Pearson product moment correlations between the importance and likelihood cluster ratings were in the moderate-high range (i.e., 0.51). Figure 12 shows differences in average importance and likelihood ratings on a pattern matching ladder map.

Figure 12

Pattern Matching Ladder Map for the Parent Focus Group: Zambia

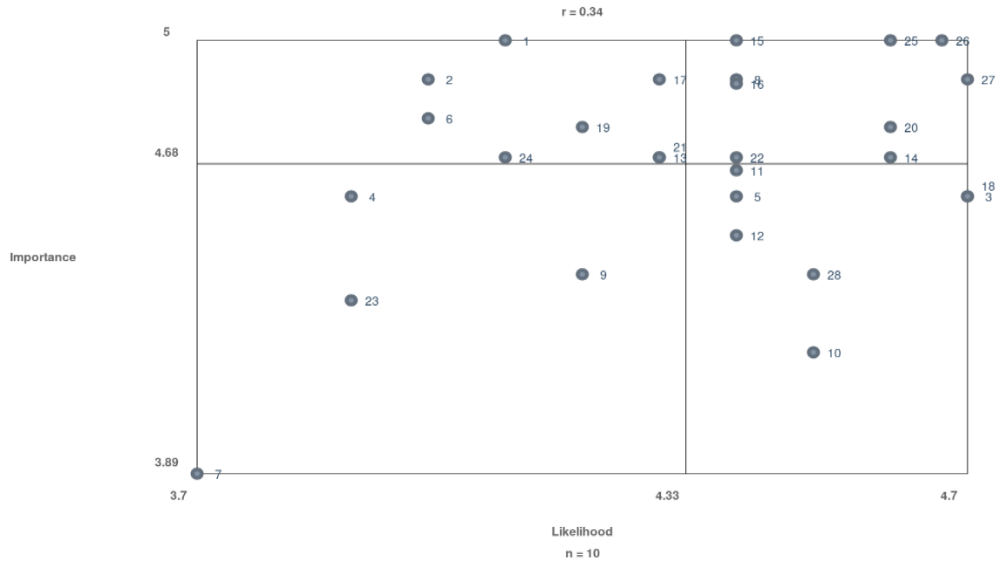


Go-Zone Analysis. The bivariate go-zone analysis showed that majority of the statements generated were plotted on the top half of the map. However, about a third of the statements were plotted in the top right corner indicating that these statements were perceived as the most likely and most important. Since these statements represent the best targets for intervention, they are presented in table 10. The map also reveals that parents perceived statement 7 (i.e., *To get access to surgery to remove the uterus*) as the least likely and least important statement. Therefore, this will definitely not be a good target for intervention efforts. Figure 13. shows the bivariate plot of each statement generated by parents on the two rating scales (i.e., importance and likelihood).

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Figure 13

Go-Zone Analysis for the Parent Focus Group: Zambia



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Table 10

Recommended Targets for Intervention: Zambia

Focus Group	Cluster Name	Statement #	Statement
Parent	Public awareness and sensitization	15	To be protected from discrimination from other children.
		16	For their conditions to be understood by society.
	Child training	8	For their survival skills to be identified.
		20	To have institutions that take care of children with disabilities. .
	Protection from abuse	22	For religious institutions to take of children with disabilities not only adults.
		26	For their teachers to monitor and ensure that they are not abused by their peers.
	Policy and practice within school contexts	27	For their teachers to ensure that they are comfortable in the school and not afraid.
		25	For government to continue supporting schools that take care of children with disabilities.
		14	To be able to relate well with their siblings.
	Service Providers	Independence	4
12			They will be allowed to gain skills that will allow them to become economically independent.
Educational opportunities		1	That they will have opportunities to go to school.
		2	That they will be provided with quality education.

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Personal and public awareness	26	There will be greater emphasis on creating awareness on issues of intellectual disabilities.
	29	That parents or primary caregivers will know the specific disability that each child has at an early age.
Health and gender-based awareness	22	They will know the difference between right and wrong.
	21	They will have access to critical information (e.g., HIV/AIDS education, climate change issues).
	24	They will be able to resist inappropriate sexual advancements made to them.
Equal rights and opportunities	27	They will be well integrated into society.
Parental Involvement and Training	34	That parents of children with disabilities will be educated on the specific disabilities of their children.
	35	That parents of children with disabilities will be provided with adequate information on how to help their children.
Equal social rights and opportunities		
	9	They will not be isolated from others in the society.

Service Provider Focus Group

Multidimensional Scaling and Cluster Analyses. Multidimensional scaling techniques produced a point map after 25 iterations with a stress value of 0.2701, also below the 0.365 cut-off (Kane & Trochim, 2007). Figure 14 shows the point map depicting the distribution of generated statements.

Figure 14

Point Map for the Service Provider Focus Group: Zambia

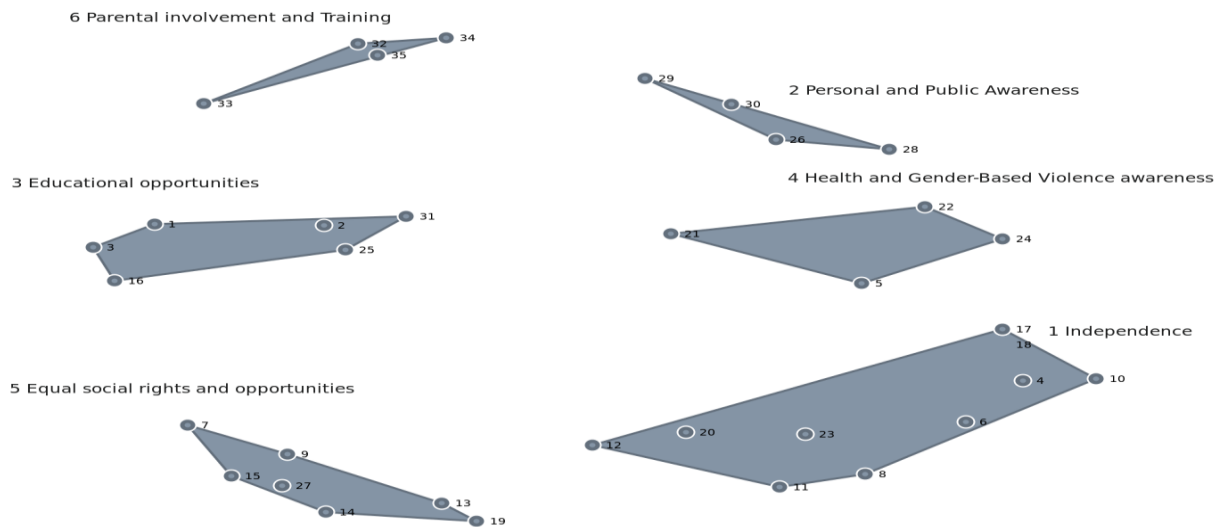


Using hierarchical cluster analysis, a 7-cluster solution was selected, after discussion, on the basis of conceptual clarity of contents in each cluster, fit with the data and the number of times items within that cluster were more likely to be grouped together by different participants (see. Figure 15). Clusters 4 and 5 were however combined since they contained theoretically similar content and were proximally located, suggesting that participants were more likely to group items in these clusters together in comparison to all other statements. Consequently, the final solution contained 6 clusters which were labelled: *independence, personal and public awareness, educational opportunities, health and gender-based violence awareness, equal*

social rights and opportunities, and *parent involvement and training*. Cluster labels and their corresponding average importance and likelihood ratings are presented in table 9. The contents of these clusters are described subsequently: the *independence* cluster contained statements on personal and economic autonomy; *personal and public awareness* contained statements about understanding the presentation of diverse disabilities; *educational opportunities* contained statements about the desire for children to receive quality educational experiences; *health and gender-based violence awareness* contained statements about access to and information about health risks; *equal social rights and opportunities* contained statements about societal involvement and access to society, and *parental involvement and training* contained statements about enhancing the skill set of parents responsible for the care of these children.

Figure 15

Cluster Map for the Service Provider Focus Group



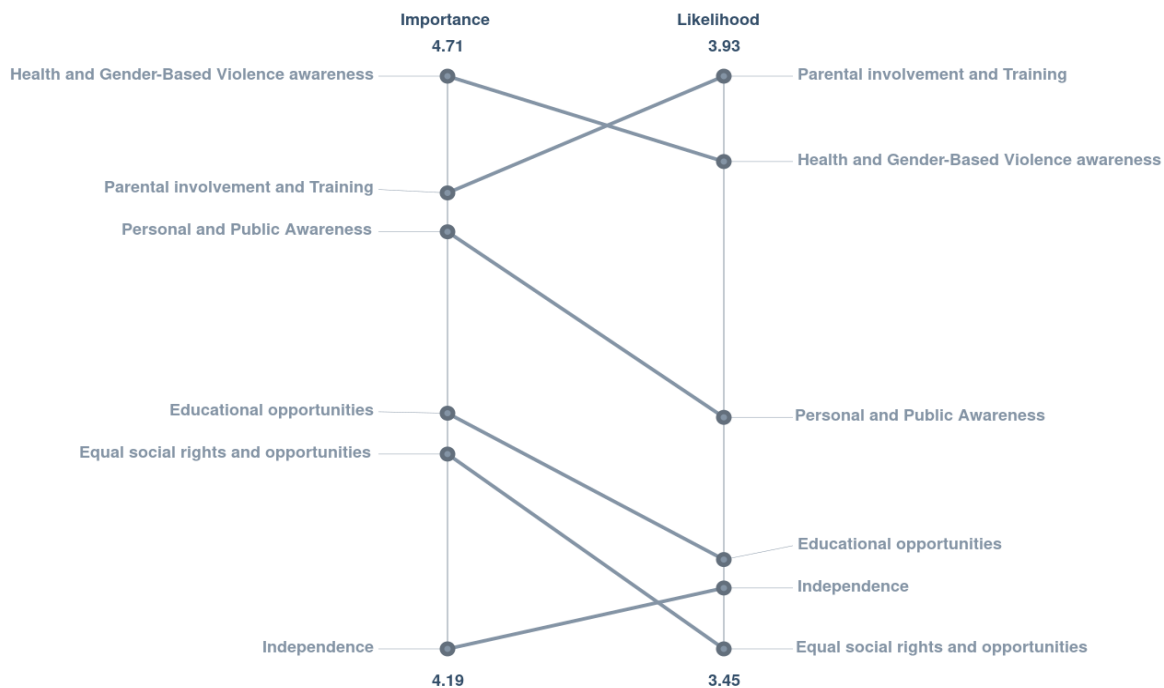
Pattern Matching Analysis. Average importance ratings for each cluster, were generally high across clusters (i.e., 4.19-4.71). Service providers rated *health and gender-based violence awareness* as comparatively more important than all other clusters. *Parental*

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involvement and training received the second-highest importance rating followed by *personal and public awareness, educational opportunities, equal social rights and opportunities, and finally, independence*. Average likelihood ratings were generally lower than average importance ratings (i.e., 3.45-3.93). However, here, *parental involvement and training* emerged as the highest rated cluster, followed by *health and gender-based violence awareness, personal and public awareness, educational opportunities, independence, and equal social rights and opportunities*. The correlation matrix between importance and likelihood clusters was high ($r=.83$). The corresponding pattern matching ladder map is shown in Figure 16.

Figure 16

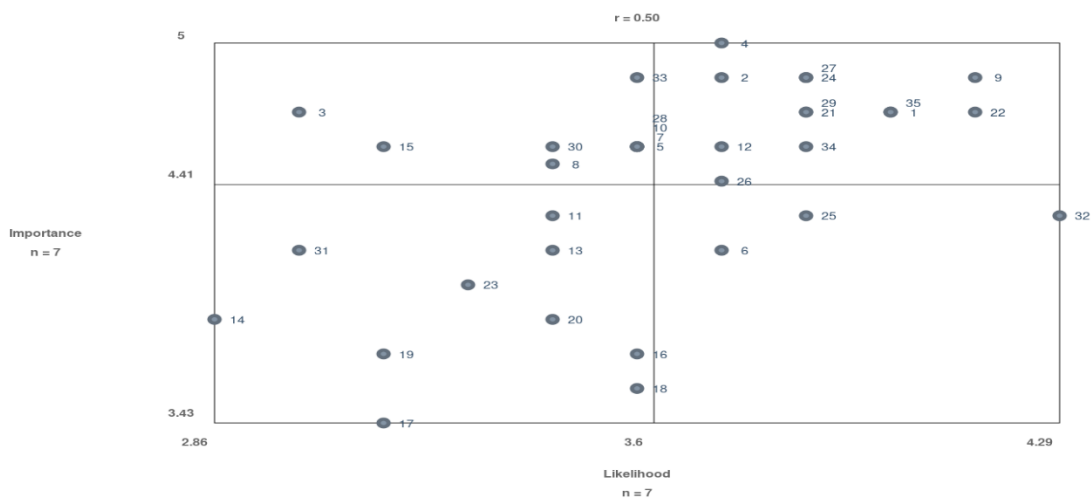
Pattern Matching Ladder Map for the Service Provider Focus Group:Zambia



Go-Zone Analysis. Figure 17 illustrates in a bivariate plot, each statement generated by service providers on the two rating scales (i.e., importance and likelihood). The plot shows that while fewer statements fell in the top left and bottom right quadrants, most fell in the top right and bottom left quadrants. It shows a clear difference between what service providers perceive as both important and likely as well as what they perceive as unimportant and unlikely. Table 10. Contains a list of statements in the top right corner considering their potential for intervention development.

Figure 17

Go-Zone Analysis for the Service Provider Focus Group: Zambia



Quantitative Analysis

In study phase 2, surveys were created using the statements obtained from both the parent and service-provider focus groups that required participants to rate the perceived importance and likelihood of each of the statements generated on a 5-point Likert scale. These surveys were distributed to a larger group of participants described below. Subscales representing the clusters that emerged from the parent and service provider focus group

analyses were created. However, given that there is variation in the clusters from the parent and service provider focus groups, data originating from the parent focus group was treated as separate from the data originating from the service provider group.

Parent Demographic Information. Thirty-three parents completed the questions. However, data from two parents were excluded because their children did not have either intellectual disability or autism. Twenty parents (64.5%) were female, and all thirty-one parent participants were Christian and of Zambia nationality. About a third of the sample reported their highest level of education as a senior high school diploma (30.3%). Additional demographic information is presented in table 11.

Service Provider Demographic Information. Forty-eight service providers composed of special education teachers ($n = 28$), health workers ($n = 12$), and other staff of organizations serving children with special needs ($n = 8$), completed the surveys. All service providers were Zambian and all except one who did not endorse any religious affiliation were Christian. Thirty-nine (81.3%) were female, and the most frequently endorsed category for the highest level of education was a teaching/nursing diploma ($n = 13$). Additional demographic information is provided in table 11.

Table 11

Additional Demographic Information for Survey Participants: Zambia

	Parents				Service Providers			
	<i>N</i>	%	<i>M</i>	<i>SD</i>	<i>N</i>	%	<i>M</i>	<i>SD</i>
Age			40.05	10.22			36.54	8.02
Education								
High School Diploma or less	5	16.1			1	2.1		
Senior High School diploma	10	32.3			6	12.5		
Vocational/Technical training	3	9.7			5	10.4		
Teacher training/nursing diploma	5	16.1			13	27.1		
HND/diploma	3	9.7			7	14.6		
Bachelor's degree	3	9.7			11	22.9		
Professional	1	3.2			5	10.4		
Missing	1	3.2			0	-		
Total	31	100.0			48	100.0		

Preliminary Analysis. Data were aggregated based on the 7-cluster and 6-cluster themes that emerged from the parent and the service provider focus group analyses respectively. Thus, there were seven aggregated clusters each for the importance and likelihood ratings from the survey developed using the Zambia parent focus group data, and six aggregated clusters each for the importance and likelihood ratings from the survey developed using Zambia service provider focus group data. The Means and Standard Deviations for each importance and likelihood cluster in each survey are presented in table 12.

MANOVAs were used to probe mean differences in each set of clusters by type of service provider, to determine whether service providers were similar enough to be grouped into a single “provider” group. No statistically significant differences emerged among the three provider groups (i.e., special education teachers, health workers, and other staff) on either the importance or likelihood ratings. As such, data from all service providers were combined for the main analysis.

Table 12

Means and Standard Deviations for the Importance and Likelihood Clusters from Each Focus Group- Zambia

		<i>M</i>	<u>Importance</u> SD	<i>M</i>	<u>Likelihood</u> SD
Parent Focus group	Social Skills	14.09	1.57	16.47	3.11
	Public Awareness and sensitization	14.17	1.31	16.17	3.35
	Policy and practice within school contexts	17.53	1.89	12.60	2.80
	Independence	18.17	2.18	12.51	2.55
	Child Training	18.57	1.91	16.61	3.29
	Government assistance	18.86	1.62	16.06	4.09
	Protection from abuse	14.12	1.43	11.50	3.58
	Service Provider Focus group	Educational opportunities	27.36	2.30	23.49
Parental involvement and training		18.95	1.59	17.25	3.11
Equal social rights and opportunities		31.96	3.26	27.01	7.24
Independence		42.93	5.72	37.81	9.72
Health and gender- based violence awareness		18.64	1.92	16.04	3.77
Personal and Societal awareness		18.13	2.00	16.22	3.64

Main Analysis. Four separate one-way MANOVAs were conducted (i.e., two for the parent focus group-based survey, and two for the service provider focus group-based survey) reflecting the ratings obtained. For each analysis, participant group (i.e., parent vs service provider) served as the independent variable, while the set of clusters (i.e., set of importance clusters or set of likelihood clusters) served as the dependent variable.

MANOVAs were used to probe group differences in each set of clusters by participant type (i.e., parents or service providers). The MANOVA probing differences in the set of parent focus group *importance* clusters by participant type (i.e., parents or services providers) was not significant (Wilks' $\Lambda = .915$ $F_{(6,57)} = .512$, $p = n.s.$, partial $\eta^2 = .085$). Similarly, the MANOVA probing differences in the set of ZPFG *likelihood* clusters by participant type was also not statistically significant (Wilks' $\Lambda = .930$ $F_{(8,54)} = 9509.45$, $p = n.s.$, partial $\eta^2 = .070$).

The final two MANOVAs probed differences in the set of service provider focus group importance (Wilks' $\Lambda = .857$ $F_{(6,58)} = 1.61$, $p = n.s.$, partial $\eta^2 = .143$) and likelihood clusters by participant type (Wilks' $\Lambda = .786$ $F_{(8,49)} = 1.66$, $p = n.s.$, partial $\eta^2 = .214$). These were also not statistically significant.

Discussion

Most studies on parental expectations have been conducted in Western countries and show that parental expectations influence the developmental trajectories of their children. However, to date, little is known about the expectations that parents, particularly parents in less developed countries, have for their children with developmental disabilities like intellectual disabilities or autism. The current study used a cultural psychology framework—the developmental niche model—to examine parental expectations for children with intellectual disabilities or autism in two African countries: Zambia and Ghana. Recognizing that service providers (i.e., special education teachers and health workers) are an important component of the developmental context of these children, the study also explored service-provider expectations for these children. Results revealed cross-cutting and also country-specific expectations that parents and service-providers had for children with intellectual disabilities and autism. Findings from Ghana also showed that the parent and service-provider groups also differed in their perceptions of the importance and likelihood of particular statements that emerged from the focus groups.

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For Ghana, findings indicate that parents of children with intellectual disabilities or autism identified five main clusters of expectations for their children: *independence, acceptance and inclusion, education, access to government resources, and healthcare*. On the other hand, service providers identified nine main clusters of expectations: *independence, love and acceptance, educational rights and opportunities, educational policy and practice, government policy and involvement, equal social rights and opportunities, vocational rights and protections, professional and caregiver training, and involvement of religious institutions*. Each theme that emerged in the parent group overlapped with a similar theme in the service provider group. However, unique themes were also evident in the service provider group. Within-group analyses showed that while some clusters had relatively high average importance and likelihood cluster ratings, other clusters showed greater variability between these ratings. Comparative average cluster ratings also helped situate these findings and have potential for policy implications (these are discussed later).

For Zambia, parents of children with intellectual disabilities or autism identified seven main clusters of expectations for their children: *independence, public awareness and sensitization, policy and practice within school contexts, training, protection from abuse, government assistance, and social skills*. On the other hand, service providers identified six main clusters, some of which overlapped with the parent clusters. Specifically, they identified: *independence, personal and public awareness, educational opportunities, health and gender-based violence awareness, equal social rights and opportunities, and parental involvement and training*. Within each group, average ratings of importance and likelihood showed that while some clusters were perceived as both important and likelihood, many clusters evidenced variability in these ratings. Comparative average cluster ratings of importance and likelihood also yielded insights that could inform policy development. Quantitative analyses showed that

there were no statistically significant differences between parents and service providers on either the likelihood nor importance ratings in the Zambia sample.

Link to Theory

Each cluster theme that emerged from the focus groups sheds light on the contextual and cultural landscape of the regions from which data was collected. In both countries, participants responded to the same prompt requesting expectations for children with intellectual disabilities or autism, and in both cases participants were able to describe detailed expectations for these children. Importantly, parents and service providers did not limit themselves to outcomes within the child's control, but instead highlighted expectations they had for the community or society regarding these children's needs. As such, expectations for these children were tied strongly with expectations about the kind of environment that the child ought to live in or the experiences they should have. This is consistent with Super et al.'s (2011) assertion that child development is the product of the child's setting, the customs of child-care in that setting, and the psychology of the caregiver. For instance, service providers in Ghana desired that children's parents and other professionals be trained on how to effectively cater to these children's needs. Parents in Ghana and Zambia also expressed their expectation that families of children with disabilities receive consistent, extensive support from their respective governments.

The overlap, coupled with an expansion upon themes that have been reported in other studies, and the inclusion of new themes also highlights Nsamenang's (1992) point that despite the development of global standards, many African countries maintain and incorporate culturally and contextually relevant aspects that are unique to them despite being forced to adopt western perspectives. By collecting data in English within the capital cities of two countries—Accra and Lusaka—our findings may be more representative of current global standards than they would have been had we collected data from other and more rural parts of these countries. Yet, even

so, factors like the impact of etiological beliefs about children with disabilities and the social discrimination that often results from it, appears to cut across the many different cluster themes that emerged from the focus groups.

A Note on Similarities Between Countries

Africans are by no means a monolithic group and the findings presented here— particularly findings that are unique to each country— clearly demonstrate this. That being said, the findings also highlight some cross-cutting themes. For example, in each of these countries, the problem of social discrimination, the isolation of persons with disabilities and the effects that these practices have on children’s lives were evident in the expectations expressed (Kassah et al, 2012; Mung’omba,2008; Muzata, 2019; Oti-Boadi, 2017; Oti-Boadi & Kwakye-Nuako, 2020). Although the etiological beliefs associated with these practices are deeply rooted in indigenous culture (Botts & Owusu, 2013; Kassah et al. 2012; Naami & Hayashi, 2012; Oti-Boadi, 2017), which is dynamic and always evolving, the effects of these beliefs persist and continue to affect multiple aspects of life. This finding is closely associated with another theme, common to both countries: the need for awareness and training.

The call for increased societal awareness, particularly through education and training, was an important theme, but had some nuance across the two countries. While parent and service providers in Zambia shared expectations for greater societal understanding and awareness of children with disabilities, parents and service providers in Ghana shared expectations about greater societal acceptance and less discrimination. This is not dissimilar to Poon’s (2013) finding that parents in Singapore, identified a limited awareness of disabilities among the general population as one of the factors limiting community integration for their children. These findings highlight a need for widespread national efforts that target awareness of children with disabilities and issues pertinent to their livelihood. In Ghana for instance, policies aimed at facilitating the employment of persons with disabilities into organizations and

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reinforcing these organizations exist (Botts & Owusu, 2013). However, the contributions that persons with disabilities can make to these organizations have not been made apparent. Widespread education efforts may highlight these possibilities and increase employment opportunities for persons with disabilities.

Independence was another cross-cutting theme both across and within country. Notably, despite the fact that this theme was raised in each of the four focus groups, not a single parent nor service provider mentioned specific expectations about independent *residential arrangements*. Given that the focus on residential independence is common, in the research literature in the West, (Ivey, 2004; Kirby, 2016; Magil-Evans et al, 2001), this may seem a surprising finding. However, in an African context this may be accounted for by a cultural orientation toward communalism or collectivism especially around child-care. That is, it is normative to find typically developing children well beyond the age of 18 still living with their parents as the expectation is that they will move out when they have transitioned to adulthood, which in most cases is marked by marriage (Boateng & Ampofo, 2016). Therefore, it is rare for young people to move out to stay on their own, and children with disabilities would be similarly situated and may in fact never move out. In the absence of marriage, there are few factors beyond tragedy and discrimination, that will necessitate an independent, self-imposed isolation.

Both parent focus groups had an education cluster, and expectations for segregated education for children with different kinds of disabilities emerged. This was surprising considering the purported advantages of inclusive education (Loreman, 2007; Xu & Filler, 2008) and parents own desire for greater societal integration evidenced in this study. Although this finding warrants specific inquiry, it may arise from parents' desires for specialized educational experiences for their children. Children with special needs who are enrolled in inclusive settings that have few personnel with the requisite training often fall behind their peers and are sometimes neglected altogether. This is even more likely when children are enrolled in

classrooms with large teacher-to-student ratios, a phenomenon very common in many Ghanaian and Zambian schools, where the average class size is 40. Consistent with findings from some Asian-Pacific countries inclusive education is not the preferred educational option for children with disabilities (Elton-Chalcraft et al., 2016; Low et al., 2018). Elton-Chalcraft and colleagues (2016) found that most parents, teachers, and children with disabilities in Bangalore, India, preferred segregated educational opportunities for children with disabilities. Reasons cited for these included perceptions of unsuitable curricula in the inclusive schools, and a lack of individualized attention needed by children with disabilities. Another study, conducted in Ghana, also found that some reasons posited for the persistence of segregated education was a perception that these settings had more dedicated teachers, and that inclusive education settings left children more vulnerable to discriminatory practices. Further, there were concerns expressed about the curriculum in inclusive settings not being optimal for children with disabilities, and that segregated settings sometimes served as intensive intervention sites that prepared children for more inclusive settings (Kassah et al., 2018).

Lastly, government assistance was a theme that was common to both countries. While both countries have drafted disability policies (Asante & Sasu, 2015; Cleaver et al., 2017; Mung'omba, 2008), much remains to be done to facilitate the optimal development of children with disabilities in these countries.

Country-Specific Discussion

In the subsequent paragraphs, a more detailed, country specific discussion about the findings that emerged from the focus groups and surveys is presented. A country-specific discussion is warranted because data from each country highlighted specific contextually relevant themes that were unique to that context (e.g., the themes of religious involvement and gender-based violence in Ghana and Zambia respectively). Moreover, even in cases where themes appeared to overlap, a closer examination of the content of the clusters showed that

they were nuanced in ways that reflected the current historical time period in each country. We begin by discussing the results that emerged from Ghana, and subsequently discuss results that emerged from Zambia.

Ghana

Parents and service providers shared overlapping expectations for children with intellectual disabilities or autism, that are also consistent with findings from previous studies. They include themes pertaining to: love, acceptance and social inclusion; independence and religious autonomy; and education and training. However, a closer examination of these themes reveals a more nuanced picture of expectations that better reflects the cultural and contextual Ghanaian environment. These expectations are discussed below.

First, the theme of acceptance and social inclusion, which emerged to some extent in both focus groups, captured within the clusters of love and acceptance, acceptance and inclusion, and equal social rights and opportunities, is consistent with themes that have been explored in other studies (Ivey, 2004; Mutua & Dimitrov, 2001; Papay & Bambara, 2014). Ivey, (2004) and Poon (2013) conducted studies in the United States and Singapore respectively, and used measures that capture aspects of this theme. Ivey found that parents expectations of community acceptance for their children were high, whereas Asian parents were more skeptical. The finding from Ghana extends this theme further by including specific references for parental and societal love, in addition to community acceptance. Indigenous traditions in the country depict children with disabilities as cursed by the gods, and therefore less human (Botts & Owusu, 2013; Kassah et al. 2012; Naami & Hayashi, 2012). In the past, such children were killed, kept isolated from other family and community members, sometimes chained and deprived of food, and in general treated with little respect (Kassah et al., 2012). It is therefore likely against this backdrop that both parents and service providers shared specific expectations for love within and outside a child's proximal environment. Differences in within group

perceptions of importance and likelihood for each focus group may stem from the perspectives used as reference point in responding. While parents used themselves and other family members as a reference, service providers' responses are more likely to have been driven by their professional and societal observations. If true, it is an encouraging finding as it indicates that greater acceptance is being witnessed in the child's proximal environment. However, it also reveals that these patterns are not yet reflected in the larger society.

A second theme that emerged and has also received significant attention from previous studies was the theme of independence. Within both focus groups the theme was endorsed as important, but likelihood ratings were slightly lower (though still relatively high). The theme, composed of expectations for self-care and self-reliance, is consistent with its conceptualization in other studies (Anderson, et al., 2016; Carter, et al. 2012; Kirby, 2016). The relatively high ratings evidenced here may be the result of the training efforts of special education centers— from which most participants were sampled— that specialize in teaching important life skills, in addition to other goals (Kassah et al., 2018). Of interest, both parents and service providers also identified religious autonomy, a variable that has also emerged in previous studies (e.g., Ivey, 2004), as a component of independence. Several western-based studies also examined expectations for residential independence (e.g., Kirby, et al. 2016). However, in this study, neither parents nor service providers shared this as one of their expectations for these children. This may be attributed to cultural practices that dictate that children live with their parents, often in family homes, until they are “matured” (i.e., Boateng & Ampofo, 2016). Thus, maturity (or marriageability) may be assessed prior to residential independence in this culture.

Like findings from Sosnowy et al. (2018) and Bush et al. (2018) which showed that parents and service providers had educational expectations for their children, parents in Ghana also shared expectations for their children to benefit from diverse educational opportunities such as college, high school, and vocational training experiences. Yet, like the previously discussed

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themes they extended this theme by also highlighting school context expectations for their children. These included statements such as expectations for their children to be educated in schools with specialist teachers; be accepted into mainstream/inclusive schools; have access to educational resources, etc. These statements reflect the current state of the educational system in Ghana. Despite the enactment of laws such as the Education Act of 2007 that seek to ensure that all children have access to inclusive education, many children with disabilities are deprived of this opportunity. The exception is children with disabilities from households with high socio-economic status who are able to secure private schooling for their children. A Strategic Education Plan (SEP), drafted in 2010, set as one of its targets, the goal of attaining the full inclusion of children with special needs in mainstream schools by 2015 (Ministry of Education, 2010). However, currently, less than 1% of children with special needs are educated in public/government funded institutions and a new SEP was drafted in 2018 with the goal of achieving 2% inclusion in public mainstream basic schools by 2030 (Ministry of Education, 2018). Within focus group findings which showed that parents importance ratings were almost as high as the perceived likelihood ratings, while service providers rated importance higher than likelihood, may be the result of parents attempts to secure the best educational opportunity for their children. Unlike in the United States where children are often legally bound to attend schools in their district, parents in Ghana face no such restrictions, thus parents beliefs in the educational opportunities they have secured for their children may explain these high ratings. . On the other hand, the differences witnessed in service provider responses may allude to the variability that exists in many of these educational establishments and the fact that not all parents are able to secure the best educational experience for their child.

Within the Ghanaian sample, four unique themes emerged across focus groups: healthcare, professional and caregiver training, religious involvement, and access to government resources. Like other themes discussed above, the contents of these themes

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covered both expectations for a child's attainment of specific targets or goals, and expectations that the societal context should provide specific supports for children's disabilities. The within group ratings in each of these clusters are congruent with current practices in Ghana. Parents and service providers shared expectations about the need for parental access to healthcare services and professionals, as well as ways to improve caregiver skills and capabilities to support optimal development among children with intellectual disabilities or autism. Although parents perceived healthcare professionals as reasonably well-equipped to serve children and their families, service providers were more skeptical and perhaps rightly so. For example, Wireko-Gyebi and Ashiagbor (2018), in their study in Ghana, found that health worker's knowledge on autism was generally low, and the only factor that differentiated between autism knowledge among the health workers was prior exposure to a patient. Service providers also shared specific expectations pertaining to parents. Although a few not-for-profit organizations have spearheaded efforts to enhance parental awareness (Buffum, 2012), many parents remain unaware of the nature and implications of a child's specific disability. The lower likelihood ratings by service providers evidenced here attest to this.

Service providers also shared expectations for greater participation and involvement of children with disabilities in religious institutions. The high importance and likelihood ratings evidenced here may be attributed to at least three factors. First, many studies examining coping strategies among families dealing with disabilities in Ghana find that faith in God is often listed as one of these strategies (e.g., Oti-Boadi, 2017). Second, studies show that many parents also hold on to the belief that their children will one day fully-recover from their specific disabilities and others actively seek out this cure in prayer meetings and prayer camps (Botts & Owusu, 2013). Third, some religious institutions actively support people with disabilities and spearhead efforts to enhance the lives of persons living with disabilities in Ghana. The presence of religiosity as a key cluster in the Ghanaian sample, may serve as a call to action in a context

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where social discrimination against persons with disabilities is pervasive (see Achuroa, 2019; Botts & Owusu, 2013; Oti-Boadi et al., 2020). A case in point, in 2019 a local religious group announced plans to develop an “ability village” on a 2,000 acre plot of land that would accommodate (i.e., house), and provide subsidized medical care, vocational training, and education to persons with disabilities (Afany-Dadzie, 2019).

Study findings also revealed between group differences on some clusters that warrant discussion. Parents and service providers differed in their importance and likelihood ratings for *independence, education, and love and acceptance*. Mean differences in both the importance and likelihood criteria for *independence* align with previous literature as well as prevailing Ghanaian customs, and the focus of some special education centers (Ivey, 2004; 2007). However, some items within the clusters such as expectations for marriage and childbearing, drew very different reactions from both groups. While parents felt it was very important and likely, these two statements drew some of the lowest mean values from service providers. Ivey (2007) also found that teachers rated expectations for childbearing as the least important and least likely in her study. Discriminatory practices in Ghana and the belief that disabilities are the result of curses, and thus transferable to children, significantly lower the marriage prospects of people with disabilities in the country (Bekoe, 2018), and may be associated with the lower service provider expectations. Similarly, discriminatory practices may also account for the differences between parent and service provider’s perceptions of expectations for love and acceptance. Yet, the higher scores evidenced by parents may be indicative of more conducive proximal contexts where these children reside.

It is also important to note that there were some differences among service provider groups. These differences may be attributable to the amount of time that personnel from the different occupational categories spend with these children. Health workers, composed mostly of nurses in this study, spend less time with these children in comparison with teachers and

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teaching aids who spend an average of 40 hours each week with these children. Group level differences emerged for importance ratings and showed that parents and health workers differed on their expectations of independence, while teachers and health workers differed on expectations for vocational opportunities. Differences on the independence cluster may be explained by the fact that it contained fewer polarizing items such as marriage and childbearing which service providers were less likely to endorse in this study and have reported similar reticence about in other studies (Ivey, 2007). Longer periods of exposure to these children in educational settings and teachers' personal observations of the effect that the acquisition of life and vocational skills has on these children and their families (Kassah et al., 2018), may have contributed to similar importance ratings between teacher and parents.

Parents perceptions that independence was the least likely outcome for the children in the focus groups, suggests greater efforts need to be put in place to increase the chances of an increased quality of life for their children. Studies show that many children with disabilities are cared for primarily by their parents; when parents are no longer capable performing this role, children are often placed in a vulnerable position and sometimes in the care of less willing caregivers. Additionally, even though the consistently high average parent ratings in this study may be indicative of optimism that may motivate their children to attain important life goals, it also important that these expectations be realistic. Unrealistic expectations may heighten parental stress which negatively impacts family dynamics, and parent and child mental health (Hsiao, 2018).

Parents and service providers (i.e., parents and teachers, and parents and health workers) had statistically significantly different likelihood ratings on love and acceptance, equal social rights, vocational opportunities, educational policy and practice, and educational rights and opportunities. Parents' reported higher likelihood ratings than service providers. Expectations associated with each of these themes highlights the disconnect between parents

and service providers in the general population. Although very few studies examine this, Ivey's findings reported in two separate studies allude to this possibility. Parents' optimism may stem from a perception of lower symptom severity in their children (Ivey, 2004; 2007). The variance in importance and likelihood findings between parents and each of these service personnel are a call to action. If service providers and parents share different perspectives of what is likely for children with intellectual disabilities or autism it may lead to the development of incongruent goals and targets. Parents and service providers need to work together and supplement each other's efforts to foster the optimal development of children with intellectual disabilities or autism.

Zambia

Three clusters that emerged from both focus groups and are congruent with previous studies were *independence, education and training, and awareness and social opportunities*. However, closer examination of each cluster reveals components that are more representation of the prevailing culture in Zambia's capital—Lusaka. Independence was an expected theme in as it emerged in Ghana and is also well-cited in the research literature from western countries (Anderson, 2016; Kirby, 2016). However, as was the case in Ghana, neither the parent nor service-provider groups shared expectations for independent residential living. In Zambia, cultural expectations which dictate that relatives care even for distant family members (Meulenbeek, 2011; UNICEF/ American Institute of Research/ University of Zambia, 2018). Clusters did reflect themes around self-care, self-reliance and economic independence, and ratings showed that parents were more optimistic about their expectations of independence than service providers.

Another theme that emerged from the focus groups was related to awareness and social inclusion. These themes, which specifically emerged in the clusters of public and personal awareness in both focus groups, and equal social rights in the service provider focus group, are

also seen in previous studies and consistent with sentiments expressed by parents in other developing nations (e.g., Poon, 2013). However, in the Zambia sample, parents and service providers expanded this theme by including statements about policy-related changes that could facilitate the optimal development of children with disabilities. Moreover, participants noted that despite being very important, these expectations were considerably less likely to occur. Several studies conducted in Zambia highlight the fact that people with disabilities face societal discrimination (Fleming, et al. 2010; Mung'omba, 2008; Smith et al., 2004) and that even the words used to describe them sometimes have negative connotations (Muzata, 2019). Moreover, Chansa-Kabali et al., (2019), in a study that sampled 488 college students, found that seventy-nine percent (79%) of them had never even heard of autism prior to their participation in the study.

Education was another theme highlighted in this study. Sosnowy et al. (2018) found that parents of children with autism possessed college expectations for their children and desired that accommodations be made by the colleges to facilitate this. Similarly, other studies highlight educational benchmarks and ask respondents to endorse the ones that best fit their expectations for their child such as high school, vocational training, diploma etc (Chiang et al., 2012; Kirby, 2016). In the current study parents and service providers shared expectations about the *kind* of educational or vocational training that they expected for these children, as well as the environmental contexts in which this training ought to occur. That is, parents specified their expectation for segregated education, and service providers clarified that their expectations were for “quality” education). These findings warrant further exploration to investigate the underlying factors associated with parents’ endorsement of segregated educational settings for their children with disabilities in Zambia.

Several unique themes emerged from the focus groups in Zambia including: health and protection from gender-based violence, social skills, government involvement, and parental

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involvement and training. Within the theme that captured expectations about health and protection from gender-based violence and abuse, parents specifically shared expectations that their female children would be protected from various forms of abuse, while service providers shared expectations for increased self-awareness on related topics. Holmes et al., (2016) found that parents expectations about their children's romantic relationships and their discussion of related topics with them, were influenced by autism symptom severity. However, no study to our knowledge has specifically addressed these expectations as strongly linked to gender-based violence. Although the theme was perceived as important in each focus group, likelihood rates were lower. These findings highlight an important contextual and cultural phenomenon. HIV/AIDs prevalence rates are high in Zambia, with a 2018 estimate of over a million people living with the disease (UNAIDS, 2020). Estimates also show that girls are more vulnerable to HIV infections. However, girls with disabilities are at increased risk for HIV infection in Zambia as a result of prevailing misconceptions that girls and women with disabilities are less likely to be sexually active and therefore free of infections (World Bank, 2010). Their lower status in society and restricted access to health facilities also add to this risk (World Bank, 2010). Higher parental ratings in this cluster suggests that parents of children with disabilities are keenly aware of the real and immediate danger gender-based violence and abuse may pose. This may be accounted for by the very active social messaging campaign that exists about gender-based issues in Zambia. Unexpectedly, during the parent focus group, the topic of forced sterilization emerged as a mechanism for protecting female children with disabilities from abuse. Although the idea, at first glance, may strike readers as unbelievably wrong and unacceptable, it is a sad but very real picture of the drastic measures that parents are sometimes compelled to take or grapple with as they consider the well-being and safety of their children with disabilities.

Parents also shared specific expectations about the development of social skills in their children. For instance, they hoped that their children would be able to relate well with other

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members of their families. Since some of the children represented in this focus group had been diagnosed with autism, the relatively high importance and likelihood ratings were surprising. However, again, it may be indicative of parent's own efforts at nurturing these skills in their children given the significance of social skills in collectivist cultures and the strong expectations for communal care in the Zambian culture specifically (Meulenbeek, 2011).

The theme of parental involvement and training, highlighted by the Zambian service providers, can be likened to public awareness. Yet it applies more specifically to parents of children with intellectual disabilities or autism. The within group differences in importance and likelihood may result from service providers interactions with parents of children with disabilities. Lastly, parents also shared expectations for government assistance for their children with intellectual disabilities or autism. Parents' expectations for continued assistance, coupled with the lower likelihood ratings for this theme, are an important call to the government for action. However, the relatively high importance and likelihood ratings for this cluster may suggest that there is some confidence in the government to come through. The confidence may be based on the government's previous efforts to enhance the lives of children with disabilities and their families.

One of the strongest themes that emerged from this study is the need for additional policy frameworks to protect the rights of persons with disabilities in Zambia. Specific policies to guide and educate stakeholders on the value of inclusive education need to be drafted and implemented. Inclusive education increases opportunities for children with disabilities to get exposed to other children in the society and vice versa. Nabuzoka and Ronning (1997) found that children who participated in a 6-month experimental study that exposed them to children with disabilities had less negative attitudes to children with disabilities in contrast to children in the control group who had no such exposure. Therefore, inclusive education may be one of means through which greater societal integration may be achieved. Additionally, some studies

showing that enrollment in inclusive settings may increase the likelihood of successful adult outcomes for children with disabilities (Martinez et al., 2012), also provide impetus for drafting specific inclusive education policies.

Limitations and Future Directions

Although this study is ground-breaking in many ways such as it utilized a mixed-methods approach with multiple stakeholders and generated a wealth of data that illustrate culturally salient constructs of expectations for children with intellectual disabilities and autism in Ghana and Zambia—the study is not without limitations. First, data was collected from residents in the capital cities of both countries and the focus groups and surveys were administered in English. Although this likely increased the ethnic representation due to the ethnic diversity in the city and helped situate our findings within the larger urban global context, it may have limited chances of obtaining other unique culturally salient expectations for children with disabilities. Future studies should consider exploring the topic among residents in other parts of the country and particularly more rural residents to garner a fuller picture, and to assess rural-urban and tribal or ethnic differences within each country.

The amount of data obtained from each country was also limited but particularly small in Zambia. While we needed at least one hundred and thirty-five data points to detect a statistically significant effect, we obtained a total of only 79 data points in Zambia. This undoubtedly impacted our results. Future studies should employ more aggressive recruitment methods to ensure that adequate sample sizes are obtained to facilitate analyses. For instance, providing more substantial compensation to participants may encourage other participants to engage in the study. The use of online survey methods might also result in higher response rates from prospective participants. In addition, future studies should also expand the sample frame to facilitate a more nuanced examination of expectations across different groups. Although this study examined differences different professionals, future studies may probe within profession

differences (e.g., general education versus special education teachers' expectations for children with disabilities). Given the importance of sibling care and responsibility within African contexts, other studies may also examine differences within familial contexts (e.g., between parents and siblings in households with children with disabilities) in their expectations for children with disabilities.

Increasing the sample size may also permit investigations into gender differences which were not possible in this study. Given Ghana's history of gender-based educational discrimination, for instance, it is plausible that parents may have different expectations for their male and female children. Mutua and Dimitrov, (2001) found that parents in Kenya, were more likely enroll male children compared to female children with disabilities in educational institutions. Yet, current educational policies providing free education, and campaigns emphasizing the significance of the female child (Asare-Danso, 2017; Nsiah, 2016), in Ghana may decrease this likelihood. Nevertheless, future studies should probe this more critically, and particularly in less developed parts of both countries, as it may have implications policy development and implementation.

This study also examined expectations for children with autism or intellectual disabilities together. The decision was based on two factors: 1) research showing that children with more severe forms of autism, and children with intellectual disabilities evidence similar symptomatology (Matson & Shoemaker, 2009); 2) current practices in both countries that decreased the likelihood that children with milder symptoms would be recruited from the segregated educational settings where recruitment efforts were focused. However, it is plausible that expectations may differ based on specific disabilities, as well as symptom severity and developmental or chronological age. Future studies show examine cross-sectional and longitudinal expectations for children with specific disabilities, at different ages, and in different types of educational settings to ascertain how these demographic factors may influence

differences across disability groups, or change in expectations over time for children with specific disabilities.

This study also had some methodological limitations. The kind of expectations shared by parents, and service providers in the study may have been influenced by perceptions of the researcher. Although the researcher was of African descent, spoke some of the local languages of the participants, and held no official position of authority beyond being a graduate student in a foreign institution, participants may have perceived her to be someone of influence in society: making them more likely to share expectations that exceeded discrete child outcomes.

Additionally, while the concept mapping methodology yielded rich data that covered several domains of the lives of children with disabilities, its capacity to generate in-depth information about specific ideas raised in the brainstorming process was limited. For instance, although parents' preference for segregated education in both countries was intriguing, the idea was not sufficiently probed in this study. Future studies should complement concept mapping methods with other strategies such as asset mapping and qualitative interviews with key stakeholders to permit more in-depth investigations into specific ideas that emerge during the concept mapping focus group sessions.

In sum, the current study identified unique and overlapping thematic expectations for children with intellectual disabilities or autism in Ghana and Zambia. These expectations have important implications for parental and societal education, professional training, and religious involvement. Professionals and all service providers ought to be trained in the appropriate care of children with disabilities and in Ghana efforts must be put in place to encourage greater participation from religious institutions. Parents should also receive adequate training and assistance in the care of their children to enhance optimal development of children with disabilities in these contexts. These recommendations must however, be taken with caution given the limitations described above.

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Appendices

Table A. Cluster Compositions for Ghana Parent Focus Group

Cluster Contents and Labels	Avg. Importance Ratings	Avg. Likelihood Ratings
1 Independence	4.63	4.30
1. To be independent.	4.60	3.80
2. To make their own decisions about where to go.	4.20	3.90
3. To make their own decisions about who to go out with.	4.33	4.20
4. To make their own decisions about life.	4.67	3.78
6. To have self-living skills.	4.70	4.20
7. To take care of themselves.	4.50	3.90
8. To learn to brush their teeth.	4.90	4.60
9. To learn to wear their own shoes.	4.90	4.70
10. To learn to dress themselves.	4.90	4.50
15. To get married.	4.30	3.90
16. To have their own kids.	4.60	4.30
39. To be potty trained	4.80	4.80
42. To be able to decide between what is right and what is wrong	4.70	4.90
38. To come to know God for themselves.	4.70	4.70
4 Acceptance and inclusion	4.70	4.60
17. To be accepted in society for who they are.	4.80	4.50
18. To be accepted in any social gathering.	4.33	4.40
19. To be treated fairly by the extended family.	4.60	4.30
20. To be treated fairly when trying to secure housing or a rental property.	4.38	4.40
21. To be loved by society.	4.60	4.70
22. To be loved by their parents.	5.00	5.00
23. For their specific conditions to be well understood by society.	4.80	4.50
27. To be treated with love by their parents.	5.00	5.00
2 Education	4.55	4.50
5. To get as much education as they desire.	4.80	4.30
11. To get access to communicative devices.	4.60	4.22
12. To attend senior high school.	4.20	4.50
13. To be enrolled in the university.	4.20	4.40
14. To have vocational training.	4.56	4.60
33. For nursery and primary school teachers to know where to refer children with disabilities.	4.70	4.50
34. To have access to inclusive education.	4.67	4.70
35. To have special schools for each condition.	4.43	4.50
36. To receive special attention in inclusive schools	4.60	4.60
37. To receive attention from teachers in inclusive schools who know how to work with children with special needs.	4.60	4.60
40. For teachers to adapt to the needs of children with special needs.	4.70	4.50
3 Access to resources	4.50	4.60

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41. To get access to promised funds from the government for children with special needs.	4.50	4.60
5 Healthcare	4.90	4.67
24. To be identified early in the hospitals by the doctors.	5.00	4.50
25. For health practitioners to communicate the conditions to parents as early as possible.	4.90	4.50
26. To be given special attention or treatment in the hospitals.	4.80	4.80
28. To be given medication that works.	4.90	4.60
30. To receive immediate treatment (i.e. they should not have to wait in line).	4.90	4.60
31. For health practitioners to know how to identify children with disabilities.	4.80	4.70
32. For health practitioners to know where to refer children with disabilities to	4.90	4.70
29. For Health professionals to treat them with patience	5	4.89

*N.B. Statement in bold represent cluster labels and all numbers are points on the respective maps.

Table B. Cluster Compositions for Ghana Service Provider Focus Group

Cluster Labels and Contents	Avg. Importance Ratings	Avg. Likelihood Ratings
1 Independence	4.63	4.14
1. To be independent.	4.78	4.22
2. To know what they need and have that need be respected once it is in their best interest.	4.78	4.11
3. To be able to communicate their wishes to others.	4.63	4.22
4. For them to come to personal faith in the Lord Jesus Christ.	4.33	4.00
2 Love and Acceptance	4.29	3.83
5. To be accepted as full members of society.	4.33	3.67
9. For them to have the same rights as everyone else.	4.33	3.89
18. That they will be loved by society.	4.44	3.67
19. That they will be loved by parents and relatives.	4.89	4.44
20. That they will be taught to love themselves as they are.	4.56	4.22
21. They will be allowed to start families of their own.	3.33	3.33
33. They will be treated with empathy not sympathy.	4.22	3.56
37. All their nutritional needs will be met (i.e., they will have enough food).	4.22	3.89
3 Equal Social Rights and Opportunities	4.40	3.68
6. That they will not be discriminated against by members of society.	4.56	3.67
7. That they would be welcome in all social settings.	4.44	3.44
8. For society to see them as humans (not second-class citizens).	4.56	3.89
10. For them to have the same opportunities as everyone else in society.	4.22	3.44
11. They should be given the same meals as other members of the society who are seen as "normal".	4.33	3.67
24. They will have access to all social amenities.	4.11	3.67
43. That children/persons with special needs will not be abused by security personnel.	4.56	4.00
4 Educational policy and practice	4.42	3.96
14. That their teachers will be well-equipped to work with them.	4.89	4.44
15. That their teachers will desire to bring out the best in them.	4.44	4.00
25. They will be accepted or included in mainstream schools.	4.11	3.65
26. That teachers in mainstream schools will be trained to work with children with special needs.	4.22	3.89
28. Every mainstream school will have at least one teacher trained to work with children with special needs.	4.44	3.78
5 Educational rights and opportunities	4.39	3.69
16. They will have access to an appropriate environment for learning.	4.44	4.00
17. They will have access to appropriate equipment, facilities and resources.	4.44	3.89

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27. That school classrooms and other facilities will be designed to accommodate children with special needs.	4.44	3.44
34. They will be allowed to attain the highest level of education possible.	4.22	3.44
6 Vocational opportunities and protections	4.44	3.77
12. They should be given opportunities to develop vocational skills.	4.33	4.00
13. They should be given opportunities to work.	4.33	3.78
29. That they will be treated fairly in the workplace.	4.44	3.50
30. That they will be paid fairly in the workplace.	4.44	3.89
31. They will not be discriminated against in the workplace.	4.67	3.67
7 Government policy and involvement	4.52	3.70
22. There will be government policies to cover the hospital bills of children with special needs.	4.33	3.89
23. That the government will allocate more funds for children with special needs.	4.78	3.44
36. They will be motivated to achieve anything they desire.	4.44	3.78
8 Involvement of religious institutions	4.52	4.15
44. Religious institutions will be involved in raising awareness about the needs of these children.	4.56	4.22
45. Religious institutions will welcome children with special needs.	4.56	4.44
46. Religious institutions will give them opportunities to express themselves publicly.	4.44	3.78
9 Professional and caregiver training	4.41	3.84
32. They will be given preferential treatment where necessary.	4.22	3.56
35. Health professionals will be trained specifically to work with children with special needs.	4.44	4.33
38. Their caregivers will be educated about their dietary needs/restrictions based on their specific disabilities and health needs.	4.67	4.11
39. That their parents and other relatives will be trained to effectively handle them.	4.67	4.44
40. That their parents will receive periodic supervision in the care of their children with special needs.	4.22	3.44
41. The general society will be educated on how to interact with children with special needs.	4.44	3.67
42. That security personnel will be trained on how to interact or handle persons with special needs.	4.22	3.33

*N.B. Statement in bold represent cluster labels and all numbers are points on the respective maps.

Table C. Cluster Compositions from Zambia Parent Focus Groups

Cluster Labels and Contents	Avg. Importance Ratings	Avg. Likelihood Ratings
1 Independence	4.74	4.28
1. To be independent	5.00	4.10
2. To be able to take care of himself	4.90	4.00
3. To be able to dress himself	4.60	4.70
4. To get a job when he is older	4.60	3.90
18. For children with disabilities to be able to feed themselves.	4.60	4.70
2 Public Awareness and Sensitization	4.93	4.37
15. To be protected from discrimination from other children.	5.00	4.40
16. For their conditions to be understood by society.	4.89	4.40
17. For children with disabilities to be understood by society.	4.90	4.30
3 Policy and Practice Within School Contexts	4.69	4.56
12. To be literate.	4.50	4.40
26. For their teachers to monitor and ensure that they are not abused by their peers.	5.00	4.67
27. For their teachers to ensure that they are comfortable in the school and not afraid.	4.90	4.70
28. For children with disabilities to have their own school, not mixed with other mainstream children.	4.40	4.50
4 Child Training	4.77	4.33
5. To be taught vocational skills	4.60	4.40
6. To have access to institutions that teach vocational skills.	4.80	4.00
8. For their survival skills to be identified.	4.90	4.40
19. To get access to institutions that will take care of children with disabilities.	4.78	4.20
20. To have institutions that take care of children with disabilities. .	4.78	4.60
5 Protection from Abuse	4.31	4.14
7. To get access to surgery to remove the uterus.	3.89	3.70
9. To have a policy that protects that female child with a disability from sexual abuse.	4.40	4.20
10. To have a policy that protects the female child with a disability from physical abuse.	4.20	4.50
22. For religious institutions to take of children with disabilities not only adults.	4.70	4.40
23. For religious institutions to take care of children with disabilities not just those severely disabled.	4.33	3.90
6 Social Skills	4.69	4.33
11. To be assisted to manage their emotions (e.g., their temper and stubbornness).	4.67	4.40
13. To be able to relate well with other people.	4.70	4.30
14. To be able to relate well with their siblings.	4.70	4.60
7 Governmental Assistance	4.80	4.33

EXPECTATIONS FOR CHILDREN WITH DISABILITIES

21. For government to make provision for children with disabilities whose parents passed away.	4.70	4.30
24. For government to help the families of children with disabilities financially.	4.70	4.10
25. For government to continue supporting schools that take care of children with disabilities.	5.00	4.60

*N.B. Statement in bold represent cluster labels and all numbers are points on the respective maps.

Table D. Cluster Compositions from Zambia Service Provider Focus Groups

Cluster Labels and Contents	Avg. Importance Ratings	Avg. Likelihood Ratings
1 Independence	4.19	3.50
4. To be independent.	5.00	3.71
6. That they will be able to buy things for themselves.	4.14	3.71
10. They will be able to live independently (i.e., by themselves without their parents).	4.57	3.57
17. They will get married.	3.43	3.14
18. They will have children of their own.	3.57	3.57
11. That they will be economically independent.	4.29	3.43
8. Moderately disabled children will be able to earn a living.	4.50	3.43
12. They will be allowed to gain skills that will allow them to become economically independent.	4.57	3.71
23. They will be able to make their own decisions.	4.00	3.29
20. They will have the freedom to choose their own lifestyle.	3.86	3.43
2 Personal and Public Awareness	4.57	3.64
26. There will be greater emphasis on creating awareness on issues of intellectual disabilities.	4.43	3.71
28. That children with disabilities will know the specific disabilities they have at an early age.	4.57	3.57
29. That parents or primary caregivers will know the specific disability that each child has at an early age.	4.71	3.86
30. That children with specific disabilities will be counselled on the life-long nature of their disability.	4.57	3.43
3 Educational Opportunities	4.40	3.52
1. That they will have opportunities to go to school.	4.71	4.00
2. That they will be provided with quality education.	4.86	3.71
3. The ratio of special education students to teachers in each class will be small.	4.71	3.00
16. They will have opportunities to get integrated into mainstream schools.	3.71	3.57
25. They will be exposed to technological advancements.	4.29	3.86
31. That each child with a disability will have opportunities to access one-on-one tutoring.	4.14	3.00
4 Health and gender-based violence awareness	4.71	3.86
5. That they will be able to access health facilities by themselves.	4.57	3.57
21. They will have access to critical information (e.g., HIV/AIDS education, climate change issues).	4.71	3.86
22. They will know the difference between right and wrong.	4.71	4.14
24. They will be able to resist inappropriate sexual advancements made to them.	4.86	3.86
5 Equal Social Rights and Opportunities	4.37	3.45
7. Moderately disabled children will be given vocational jobs.	4.57	3.57

EXPECTATIONS FOR CHILDREN WITH DISABILITIES

9. They will not be isolated from others in the society.	4.86	4.14
13. They will have equal opportunities to participate in social events happening in the country (i.e., participate in traditional ceremonies).	4.14	3.43
14. They will have equal opportunities to help in organizing social events happening in the country.	3.86	2.86
15. They will be allowed to express their views on national issues.	4.57	3.14
19. They will have freedom of religion (i.e., free to choose their own religion).	3.71	3.14
27. They will be well integrated into society.	4.86	3.86
6 Parental Involvement and Training	4.61	3.93
32. That parents of children with disabilities will accept their children.	4.29	4.29
33. That parents of children with disabilities will provide their children with the right education opportunities that suit their needs.	4.86	3.57
34. That parents of children with disabilities will be educated on the specific disabilities of their children.	4.57	3.86
35. That parents of children with disabilities will be provided with adequate information on how to help their children.	4.71	4.00

*N.B. Statement in bold represent cluster labels and all numbers are points on the respective maps.

Vita

Princess-Melissa Washington-Nortey was born on September 17, 1990, in Accra Ghana. She graduated from Achimota Senior High School in Ghana in 2008 and received a Bachelor of Arts in Psychology from Ghana's premiere university: The University of Ghana. Subsequently, she enrolled in and completed two master's degrees. The first was an international Master of Arts in Child Development from the University of Haifa in Israel, which she received in 2015, and the second, a Master of Science in Developmental Psychology from Virginia Commonwealth University, obtained in 2018.