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**Exploring Three Mothers' Perceptions and Lived Experiences of
Caring for and Educating their Disabled Child in
Trinidad and Tobago**

This submitted in partial fulfilment of the

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Dedication

I dedicate this thesis to my parents, Sita, and Arjoon Badloo, who I know will be proud of me as the first family member to ever reach this far in academia. I thank them for their prayers, support and for having confidence in me.

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ABSTRACT

This research aimed to increase one's understanding of caring for and educating disabled children in Trinidad and Tobago. A qualitative analysis of the narratives of three mothers was conducted using in-depth interviews. The data were coded into themes and the models of disability were used as a basis of analysis.

Four key issues emerged from the findings in response to the research questions: (1) mothers experienced psychological pressures upon diagnosis of their child's disability as well as a sense of joy and fulfillment while raising their disabled child; (2) mothers' initial perceptions of disability followed a charitable view and shifted towards a more social perspective; (3) mothers perceived themselves as the "owners" of their children and their disability which justified their willingness to assume lifelong, intense, caregiving roles; and (4) mothers perceive the government as inefficient in providing for educational and other social needs of disabled children. The research design allowed the participants to share their views, beliefs, and personal reflections on their parenting journey.

The study confirmed that mothers require additional support in caring for and educating their disabled children, which can be achieved through increased understanding of their lived experiences. By aligning more towards the bio-psycho-social model of disability, the government, society, families, and mothers themselves can gain more knowledge on enhancing the quality of care for disabled children and their primary caregivers.

The key recommendation is for the government to implement legislation, effectively addressing the need for interventional social support services at the diagnosis stage, equal access to formal schooling, and eventual employment opportunities for disabled persons which would serve to reduce the psychological burden of mothers. A greater response by the government can also address the stigma that disabled children and their caregivers face, with the ultimate goal of creating a more inclusive society and appreciation for the work mothers do.

Further research on mothers' lived experiences using a larger and more diverse population size may reveal additional information to further increase the understanding of disability in Trinidad and Tobago

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List of Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
CSO	Central Statistical Office
ECLAC	Economic Commission for Latin America and the Caribbean
EFA	Education for All
EOA	Equal Opportunities Act
ICF	The International Classification of Functioning Disability and Health
MSDFS	Ministry of Social Development and Family Services
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific, and Cultural Organization.
UNICEF	United Nations Children's Fund
WHO	World Health Organization

1 Chapter One - Background and Context

1.1 Introduction

Disability is a complex phenomenon and is rarely understood. The International Classification of Functioning, Disability, and Health (ICF) defines disability as a blanket term for impairments, limitations to activity, participation, and functionality that arise out of a person's health condition and environmental or personal factors (WHO, 2011). There is an extensive body of literature that indicates the challenges and struggles disabled persons and their caregivers face (Oliver, 2013; Landsman, 2005a, 2009b; WHO, 2011; United Nations Children's Fund, 2007). In 2011, the World Health Organization (WHO) indicated that there are 15.3% or 978 million people in the world who are living with a disability, of whom 5.8% or 106 million are disabled children.

As mothers are considered to be the primary caregivers of children (Landsman, 2005; Lalvani, 2011; Choi and Riper, 2016), it is extremely useful to understand how they raise their disabled children. Research has indicated that there is limited literature on how mothers experience caring for and educating their children (Madi, Mandy & Aranda, 2019), their perceptions of their caretaking role, and how they view the government's responsibility towards disabled children. Specifically, in Trinidad and Tobago, there is no study thus far that focuses on caretaking from mothers' perspectives in raising disabled children. Research also points to the fact that for the primary caregiver, parenting disabled children involves a unique set of circumstances (Garland Thompson, 2011). These circumstances include the trauma mothers undergo upon diagnosis of their children's condition as well as their ongoing anxiety, depression, social exclusion, and isolation which both they and their children may experience (Choi & Riper, 2016; Pillay, Girdler, Collins & Leonard, 2012). Depending on how mothers understand disability, particularly their perception of themselves as the absolute "owner" (Jeske, 1996) of their children, they may assume multiple roles which can become overwhelming (Tsai, Tsai & Shyu, 2008). Resultantly, such copious feelings could impact negatively upon their psychological well-being (Choi & Riper, 2016; Pillay, Girdler, Collins & Leonard, 2012). Hence, knowing and understanding mothers' intense caregiving roles (Woodgate et al., 2015) is critical in determining the level of support they may require.

Disabled children are a marginalized group in society (Mokhtari & Abootorabi, 2019; Singal, 2009), and this can carry implications on the ways in which they are educated, schooled, or the way they learn in general. Education to a large extent accounts for preparing students to become contributing and active members of society. Therefore, if there is exclusion and isolation of children from the formal education system, societal attitudes involving stigma and discrimination towards disabled children would prevail (Conrad, Paul, Bruce, Charles & Felix, 2010). Furthermore, mothers in their caregiving capacities may not be able to provide for their children's educational needs, such as formal schooling. As a result, understanding the way they navigate their disability experiences concerning access to schooling is critical as it relates to the future development and independent survival of their disabled children.

Additionally, the maternal caregiving experience is influenced by societal beliefs and attitudes about disabled persons. The way disability is understood in relation to societal behaviour can affect the perception and treatment of disabled children and their caregivers (Yousafzai, Farrukh, & Khan, 2011). In this regard, since disability is socially constructed, a lack of understanding by society can enhance stigma (Goffman, 1963), resulting in the exclusion and social isolation of both mothers and their disabled children. Moreover, stigma can augment the care burden through the notion of "perceived support" (Sipal & Sayin, 2013) insofar as mothers may infer that they would not receive support and consequently not pursue assistance even if needed. Societal behaviour, therefore, plays a significant role in influencing the meanings mothers may derive from their efforts to deal with the challenges associated with raising a child with a disability (Choi & Riper, 2016). Further, as the government is supposed to be responsible for the general wellbeing of its citizenry, especially the vulnerable (Choi & Riper, 2016; Mack, 2014), the way mothers perceive the government's ability to assist may influence the degree of intervention or assistance needed from policymakers in raising their disabled children.

This research will focus on the perceptions and lived experiences of mothers parenting disabled children in Trinidad and Tobago. To the best of my knowledge, there is no study conducted in this country with a specific focus on mothers. Mothers can be burdened with substantial mental or emotional stress leading to increase risk of anxiety and/or depression (Sipal & Sayin, 2013; Savari, Naseri & Savari, 2021) and which may

have implications on how they cope and manage their disabled children. Studies have shown that mothers' psychological burdens can become so extreme that they result in feelings of hate and ambivalence towards their disabled child (Harvey & Long, 2020) or, in more extreme cases, filicide (Farnsworth, 1994). The dearth of literature on this topic makes this study critical for understanding disability in Trinidad and Tobago since it would provide information from another dimension, that is from the perspective of a mother. As the principal caregiver of their disabled children, mothers' voices equate to "scripture", if one considers the almost *absolute* way they understand their children's needs from a social, individual, and community perspective (Choi & Riper, 2016). The present research seeks to give voice to this marginalized group in society by listening to their stories and learning from their experiences. It is hoped that this would generate a deeper understanding of the mothering roles in caring for disabled children.

1.2 Contextualizing Disability in Trinidad and Tobago

To gain an appreciation for the setting of this research, readers must understand the geographical, historical, and educational context of disability in Trinidad and Tobago. I hope that this research can put constructive arguments and ideas forward to sensitize policymakers around the gaps and insufficiencies in policies and practices concerning the needs of mothers and other caregivers raising disabled children. In this section, I present a historical overview of Trinidad and Tobago, a description of the country's education system, and an exploration into disability and educational developments in Trinidad and Tobago.

1.2.1 The Geography

Trinidad and Tobago is a twin-isle democratic republic situated in the southernmost part of the Caribbean (Williams, 2007). The islands became an independent nation in 1962 (Steinbach, 2012). The census report in 2011 estimated a population of 1.3 million with a composition of 35.4% East Indian, 34.2% African, 22.8% mixed, and 6.6% other or not stated (Central Statistics Office, 2011). Trinidad and Tobago is noted for having one of the strongest, and wealthiest economies in the Caribbean because of its oil and natural gas reserves (James, 2010; Williams, 2007) but it is now facing some economic difficulties because of the decline in oil prices (Persons, 2018; UNICEF, 2017). Although Trinidad and Tobago is a multi-ethnic, multi-cultural society and is relatively developed compared to its Caribbean counterparts, it carries a legacy of elitism and

imbalances of power owing to the country's historical background of colonialism and slavery (James, 2010; Libert, 2007; Pedro & Conrad, 2006). Undoubtedly, its origins of diversity in religious and cultural backgrounds potentially suggest multiple perspectives on the notion of disability.

1.2.2 A History of Disability in Trinidad and Tobago

According to Lavia (2007), historical overviews are significant because “they provide the cultural and political contexts that shape given policies and practices” (Lavia, 2007, p. 120). Historically in the Global South, under which Trinidad and Tobago is classified, provision for disabled persons has been mainly organized by religious groups or charitable organizations (Conrad et al., 2010; Lavia, 2007). Johnstone (2010) notes that disability has been historically regarded as a family issue and formalized services for disabled persons in developing countries were indeed negligible. He cited Ingstad and Whyte (1995) in observing that services for disabled persons could not be justified because the disabled were considered unproductive members of society. Such a perspective is indicative of discriminatory structures and attitudes that could be meted out to disabled persons, including disabled children. Special education, or education for disabled children as Johnstone (2010) notes, is a relatively new phenomenon in many countries of the Global South but received greater attention by the developing countries around the time of the Salamanca Statement and Education for All (EFA, 2000) goals. However, even from this time, addressing the multitude of needs and rights of disabled persons and inclusive education is still an emerging concept (Johnstone, 2010) and still poses challenges for developing nations.

Notwithstanding these challenges, the government of Trinidad and Tobago has indicated its commitment to improving the lives of disabled persons by committing to several international mandates relating to disabilities. The nation is party to the United Nations (1948) Universal Declaration of Human Rights, the Salamanca Statement (UNESCO, 1994), and the United Nations Convention on the Rights of Persons with Disabilities (WHO, 2011). Being a signatory to international treaties requires that a country meet a minimum standard of resource provision regarding the rights of disabled persons. Access to education, which is considered a right, is inextricably linked to work as it provides an avenue for gainful employment. Hence, countries that have signed these

treaties and ratified the conventions are obligated to ensure that disabled persons are equipped with the necessary education and training to meet the demands of adulthood and employment (Seetahal & Charran, 2018). The Constitution of Trinidad and Tobago embodies several national mandates which protect the fundamental rights of its citizens and safeguard against discrimination based on race, origin, colour, religion, and sex. However, there is no specific mention of disabilities within the constitution granting the freedom from discrimination, apart from the Equal Opportunities Act (EOA) of 2000. Seetahal and Charran (2018) confirm the same, stating that the Act “provides the freedom from discrimination to persons of any ‘status’ including the status of disabled persons” (p.134).

At present, no laws exist governing disabled persons in Trinidad and Tobago except for the Equal Opportunities Act (EOA) of 2000 as noted above., but there are policies in place. However, in 2013, Trinidad endorsed its commitment to the rights of disabled persons in the Declaration of Pétion-Ville² (Persons, 2018). In 2018, the government of Trinidad and Tobago revised its national policy on disabled persons but acknowledged that this legislation could be considered discriminatory towards disabled persons (National Policy on Persons with Disabilities, 2018) as all factors regarding inclusion and discrimination, specifically to employment, were not addressed (Seetahal & Charran, 2018). Consequently, the legislation on the revised policy is still to be fully implemented (Seetahal & Charran, 2018), which will have implications for the way families can access services and care for their children with a disability.

The Central Statistical Office (CSO, 2011) census report revealed that there were 52,244 persons living with disabilities in Trinidad and Tobago, of whom 3,302 or 6.3 percent were children, the latter accounting for one percent of the country’s total child population (CSO, 2011; UNICEF, 2017). Additionally, there are some programmes and services available but given the total number of disabled persons in the country, there may not be sufficient services to cater to this disadvantaged population. Existing services include the government’s provision of partial funding to several non-profit organizations which are available on the website (Government of the Republic of Trinidad and Tobago, TT Connect, 2018). These include paying school fees for students attending the National Centre for Persons with Disabilities vocational education programmes, free bus service for disabled persons, grants for the Blind Way Forward, an organization that provides

services for people with visual impairments, and funding in part to the Caribbean Kids and Therapy Organisation, a non-profit body which provides pediatric treatment for children with developmental, physical and cognitive challenges (Persons, 2018).

Understanding where the country of focus lies in terms of global data on disability as well as its history, and interaction with international and national mandates and its provision of social and educational services for disabled people is necessary. This understanding can provide a context on Trinidad and Tobago's status quo relating to disabled children and human rights. Being a signatory to these mandates, however, does not necessarily ensure equality of opportunity for all persons, particularly those with disabilities. In Trinidad and Tobago, research from several sources (Charran, 2018; Conrad et al., 2010; Lavia, 2007; Mack, 2014; WHO, 2011; UNICEF, 2017; UNESCO, 1994) has signaled that disabled children are still disadvantaged, marginalized and unable to attain the services they need for optimum development. As a result, much of the "care burden" (Green, 2003) defaults to parents, particularly mothers which this research will show. To these mothers, as to all citizens, the way disability is understood influences society's perceptions of disability specifically what it entails to care for and educate a child with a disability in Trinidad and Tobago.

1.2.3 The Structure and Nature of Education for the Disabled Trinidad and Tobago

As a former British colony, Trinidad and Tobago's education system is patterned after the structures and practices of Commonwealth countries and includes both public and private schools (De Lisle, Seecharan, & Ayodike, 2010; Williams, 2007). Hence there are remnants of the colonial past in the education system in the existing categories of schools (James, 2010; Steinbach, 2012). The twin-island republic achieved universal primary education in the 1950s and universal secondary education in 2000 (James, 2010). Almost all public schools in Trinidad and Tobago are government-assisted, meaning that they are managed by religious denominations and financially supported by the government. Children attend primary school for five years, after which they sit the Secondary Entrance Assessment to vie for acceptance into their secondary schools of choice (Steinbach, 2012). Traditional or public schools are sub-divided into government schools or government-assisted schools, which fall under the directive of the Ministry of

Education, Ministry of Science, Technology, and Tertiary Education, or, in the case of Tobago schools, the Tobago House of Assembly (Williams, 2010). Early childhood, primary, secondary, post-secondary, and tertiary education constitute the five levels of the education system in the country (Williams, 2010).

Before 1962, education for disabled persons in Trinidad and Tobago was, to a large extent, ignored and isolated by the state (Libert, 2007). In the 1940s, education for students with disabilities took place in special schools and was facilitated by philanthropic and religious groups (Conrad, Paul, Bruce, Charles, & Felix, 2010; Libert, 2007; Pedro & Conrad, 2006; Williams, 2007). Students with special needs attended institutionalized schools funded by the government (Williams, 2007). 1968 to 1993 marked the era of educational reform and was where the nation began to transform the elitist system of education. In 1980, these institutionalized schools were integrated into the government education system and are now known as special schools, with their specific boards of directors (Williams, 2007). Following this, the Ministry of Education (MOE) in 1981 formed a specialized unit to coordinate special education with a rights-based outlook on education for disabled children (Pedro & Conrad, 2006; Conrad, Paul, Bruce, Charles, & Felix, 2010; Williams, 2007). Furthermore, representatives of both government and non-governmental organizations formed an advisory committee that produced a report on a survey for handicapped children and youth in Trinidad and Tobago (Williams, 2007). The survey results influenced public awareness of the issues affecting education for this vulnerable population. Some of the issues highlighted included minimal inclusion of disabled children in regular schools, insufficient teacher training in special education, inadequate curriculum, the need for enhanced teaching methods, improved diagnostic testing for disabled children, and limited resource allocation (Williams, 2007).

As special education gained in popularity in the 1990s, there was increased international assistance towards its development. A partnership with The University of Sheffield in the United Kingdom, the Association for Special Education of Trinidad and Tobago, and the Trinidad and Tobago Unified Teachers Association (TTUTA), resulted in the training of 300 special education teachers in Trinidad and Tobago (Pedro & Conrad, 2006; Conrad, Paul, Bruce, Charles, & Felix, 2010). In 2004, the Students Support Services Division (SSSD) was formed under the Ministry of Education (Williams, 2007) and had the mandate for planning and implementing inclusive education where students

with disabilities were supposed to be integrated into regular schools instead of being segregated into special schools (Williams, 2007).

The progress towards inclusion has been slow but steady. The Trinidad and Tobago government's strides towards inclusive education is evidenced by its signatory status to international commitments such as the Salamanca Statement and the Dakar Framework for Action. Trinidad and Tobago went a step further and signed the United Nations Convention on Rights of Persons with Disabilities in 2006, which advocated for inclusive schools (Conrad, Paul, Bruce, Charles, & Felix, 2010). This reflects a move by the government to recognize the need and importance of inclusive education as a means of reducing the marginalization of children with special needs and as an avenue to build strong communities and a more cohesive society. However, despite these commendable efforts by the government to improve access to education for all disabled children, the national policy and corresponding implementation strategies have been weak (Armstrong, Armstrong, Lynch, & Severin, 2005). Consequently, disabled children are still marginalized and incapable of fully participating in the education system and in society in general.

In this regard, equal access to formal education remains a challenge for many caregivers of disabled children. As Persons (2018) noted, although Trinidad and Tobago has a well-educated population it has one of the highest differences in completion of secondary education "between working-age adults with and without disabilities in the Caribbean" (p.6). According to Persons, in 2010, "fifty percent (50%) of disabled persons had a secondary school education while eighty percent (80%) of persons without disabilities had completed secondary school" (p.6). As disabled children are not mainstreamed into the wider school system and given the lack of access to special schools for many children, caregivers, usually mothers must find alternative means for educating their children. Therefore, the lack of access to education increases caregiver stress because the integration of their children into society becomes more problematic. Some authors believe that the concept of inclusion is a social justice issue, one that calls for investment and sustainability of effort (Lavia, 2007, Conrad et al., 2010) and that the government is responsible for promoting the development of the society by establishing conditions for productive life and activities of socially vulnerable groups in society (Zvoleyko, Kalashnikova & Klimenko, 2016).

Regarding the issues highlighted on the past and current system in Trinidad and Tobago concerning education for disabled children, one can therefore conclude that the quality of education for this marginalized group is both lacking and not of a high standard. In this respect, Persons (2018) aptly cited Beckles and Hanson as saying:

“Too many children with disabilities fall through the cracks of the education system and emerge from primary or secondary institutions unable to read, write and demonstrate essential life skills. Yet they are expected to earn their own living in the same job market as persons without disabilities who have not suffered for access to quality education suitable to their needs” (Persons, 2018, p. 6).

1.3 The Significance of my Research

This research focus lies in disability studies and can broadly contribute to the extant literature regarding mothers’ experiences in parenting disabled children in the developing country of Trinidad and Tobago. The results of this study will be beneficial to society in treating disabled children and their caregivers with greater equity and dignity. It could also serve to build a more inclusive society which has been a vision of the government of Trinidad and Tobago since the 1960s (Conrad, Paul, Bruce, Charles, & Felix, 2010). This vision is reflected in the government’s commitment to various international mandates for education and disability, as mentioned previously.

Additionally, the results of the findings of this research can suggest possible actions for the country’s policymakers. Policy and legislation can trickle down to the general public, including families with disabled children, educators, and medical professionals, thereby increasing the knowledge of other stakeholders that affect the lives of mothers parenting disabled children. These stakeholders will be privy to the stories shared by mothers and the daily personal struggles endured with caring for their disabled children in the context of Trinidad and Tobago. Such data can provide valuable insight on how to craft relevant policies and legislation to meet the needs of a vulnerable group in society.

Significant also is the benefit that mothers of disabled children would derive from this study. As this research focuses on the lives and stories of mothers in raising disabled children in Trinidad and Tobago, the study could reveal findings drawing from deeply

psychological and social experiences, uncovering their day-to-day challenges, and understanding how and why mothers perceive their intensive caretaker roles as they do. Putting mothers at the centre of this research, fellow mothers of disabled children in Trinidad and Tobago can benefit from having their voices represented and take comfort in this solidarity of life journey storytelling. Furthermore, if policymakers can apply the information provided from this thesis to better the lives of mothers, then by extension, legislation could also assist mothers in their caregiving capacities.

Although this study explored the lives of mothers of disabled children, the eventual goal is to enhance the equal opportunities and quality of care and education for disabled children themselves. Therefore, the research can indicate that if mothers' caregiving burdens can be made easier by the support they may gain from enhanced policies and laws or increased understanding of disability, the quality of care for their children will also improve. Additionally, mothers' burdens and worries can also be alleviated if there is greater certainty of future survival and care for their children in the event of mothers' demise. This certainty can be made possible through enhanced policies and legislation concerning education and employment.

Finally, the benefit of this research is also for researchers who are engaging in this topic of study, specifically those researching in the area of disability in Trinidad and Tobago since this study represents the first of its kind in Trinidad and Tobago. In this regard, in the following section, I will describe my background as a researcher, as it will provide an understanding of my views and reason for engaging in this research.

1.4 My Background and Motivation for This Study

I have been an educator for the past thirty-two years. My academic background is in the field of education. After sixteen years as a teacher, I became the Manager of an Early Childhood Care and Education Centre. This Centre was a government initiative in the 1970s involving three Ministries: Ministry of Health, Ministry of Education, and Ministry of Community Development. The Centre was designed to accommodate families from low socio-economic backgrounds in a rural community at that time, and which had a high infant mortality rate.

Whilst working here, I encountered many parents wishing for their children to attend the Centre as it was a free service provided by the government and which offered both preschool and day-care services. Some of those parents had children with special needs and faced difficulty in accessing educational and care services for their young children (1-5 years old). In the course of my duties, I realized that there were not many options for mothers, and particularly single mothers, to find day-care or preschool services for children with impairments or who were disabled and fell within the 1-8 year age range. Mothers came to the Centre and sometimes pleaded for their children to be enrolled. They expressed to me that they were also restricted in being employed as they had limited social support to care for their children.

As the capacity was limited for intake at this Centre, I felt overwhelmed at times being unable to assist these mothers in securing the educational needs of their children. Additionally, this Centre being the only one of its kind in Trinidad and Tobago, represented an excellent form of inclusive education. Both children with and without impairments or who were disabled were not only accepted, but cared for, provided with meals, and taught in the same spaces or classrooms by trained professionals. On occasions where I had to refuse a mother, father, guardian, or grandparent caring for a child with a disability, I recall feeling resentment towards the system that excluded this sector of the population from equal access to educational services. I also felt guilty as I represented the government service in my limited capacity and was not able to lend support to these families.

I am a mother of three children. My personal experiences of caring for my children have led me to believe that mothers have a special and intimate bond with their children. One of my children was regularly ill as a child and I spent years of sleepless nights worrying about his health, taking him to the hospital while I left my other children at home alone, taking time off from work, and wondering how he would grow and survive on his own. I used to think that no one else could care for this child because they simply would not understand what was needed to be done or, worse, they would not treat him with the quality of care I knew only I could provide. So, *I know* what it is like to feel the pain a mother goes through with her child being ill, disabled maybe, as I believe that illness can temporarily disable anyone to some extent. However, throughout my career as an educator of young children, the way mothers parent children with a long-term illness,

impairment, or a disability, and navigating the world involving disability in Trinidad and Tobago has always been of keen interest to me.

In addition, I also had a more recent incident with disability at my workplace. As manager of the Centre where I worked, I had accepted a mother's application to have her child, who had a severe disability, attend the Centre. According to this mother, no other school would accept the child because he was prone to serious illness which caused his disability. One day, she visited my office after school, accompanied by her child. Suddenly, during mid-conversation, she stopped speaking, dropped the items from her hands onto the chair, stooped to the floor, and began speaking gently to the child, touching his nose, his eyes, her voice coaxing, trying to make him focus and listen to her. I looked on, petrified, concerned, and utterly moved by her actions and alertness. The child was having a seizure, one that could go unnoticed, as it did for me. I watched this mother attend to her child and wished there was something more I could do. I felt extremely useless at the time. She apologized and told me that "*this is how it happens*", and that is why she always needed to be alert and near him or with him as he was the priority in her life. This incident sparked my interest further in wanting to know about the experiences of mothers caring for their children who were disabled.

Throughout my professional and personal life, I have encountered many instances where disabled children and their caregivers were discriminated against and underappreciated. Engaging in this research is one way that I feel I can make a difference by contributing to the literature on understanding disability. Being exposed to the views and perceptions of mothers as the primary caregivers of their children, I believe, can provide deeper insights into what may be required to care for disabled children in Trinidad and Tobago.

1.5 The Problem Statement

There is no global definition of disability (WHO, 2011; Groce, Kett, Lang & Trani, 2011), which suggests that disability is subject to interpretation. Research has found that disabled persons constitute fifteen percent of the world's population (Saleh & Bruyère, 2018) and are categorized generally as a vulnerable and marginalized group in society (WHO, 2011). Persons who live with a disability and their caregivers may be the only ones who can truly explain both the difficult and enjoyable moments they encounter

while living with a disability. The overall problem is that disability can be generally misunderstood or misconstrued by “others” in society.

Approximately one percent (or 3,302 persons) of the population in Trinidad and Tobago are children who live with a disability (CSO, 2011). The specific problem is that the effect of disability on caregivers of disabled children in Trinidad and Tobago is rarely discussed. This lack of information can result in disability being ignored or misunderstood by society, including by mothers themselves as they may have limited knowledge or preconceived notions on disability, which could lead to eventual exclusion and isolation of both themselves and their disabled children (Hatun, Yavuz-Birben, İnce & Kalkan-Yeni, 2016). A possible reason for such perceptions can be that disability is an underexplored area of study in Trinidad and Tobago, specifically around mothers’ lived experiences.

This problem of being misunderstood has the potential to negatively impact the psychological wellbeing of mothers and can further place children at a disadvantage for receiving optimum care and development. Further, as the government is usually considered the body that is responsible for the welfare and equitable treatment of all its citizens and through its national and international commitments, it has a responsibility to care for the marginalized groups in society. Hence, the government has a crucial role to play in securing the needs of disabled children in Trinidad and Tobago.

With regards to further understanding disability, this study will examine the mothers’ experiences and perceptions of both their roles and those of the government through a narrative approach to inquiry. An advantage well within reach, I feel, is that disability may be better understood taken from a mother’s perspective which can result in the creation of laws, policies, programmes, or services that can assist mothers in their intensive caregiving journey. To ignore a more nuanced understanding of disability as it concerns disabled children in Trinidad and Tobago is to ignore the developmental and educational needs of one percent of the citizenry who are already a marginalized group in society (Armstrong, Armstrong, Lynch & Severin, 2005; Mack, 2014; Charran, 2018) and by extension, the burdens of their caregivers.

1.6 Aim and Purpose of the Study

In this study, I aim to provide an in-depth understanding of disability by exploring the lived experiences of three mothers and their perceptions in raising their disabled children in Trinidad and Tobago. To do this, I aim to uncover their perceptions of disability, as perceptions can influence the way these mothers treat and manage their lives whilst caring for their children. In examining the mothers' experiences, I will also explore the way they perceive their roles as well as their perceptions of the roles of government in caring for and educating disabled children in Trinidad and Tobago.

In explaining the purpose of the study, I will examine the justification of the Research Questions. I will then discuss the models of disability and the theory upon which I will base my analysis. The general problem that this study seeks to address is the misunderstanding of disability in the Trinidad and Tobago context. Therefore, the purpose of this qualitative inquiry is to explore specifically, the storied lives of three mothers with a focus on their perceptions and experiences in caring for and educating their children who have an impairment or a disability. The main objective is to increase the overall understanding of disability with the hope that both mothers and children would be able to benefit from the learnings provided from this investigation. In this regard, the research questions will guide the aims and objectives of the study.

1.6.1 The Research Questions

Creswell (2009) denotes that in qualitative inquiry, researchers state research questions, as opposed to quantitative studies where they use hypotheses. The questions can have one of two forms: one central research question or one central research question containing sub-questions. These questions seek to address the central concept of the study and are usually consistent with the methodology of qualitative inquiry. Creswell also notes that the words "how" or "what" are usually used to convey this "open and emerging design" of qualitative inquiry, whereas the word "why" suggests a cause-and-effect relationship which characterizes the positive paradigm of inquiry (p. 131). The research questions that I used did not contain a central question as such but included a "what" question as well as the "how" questions. Consistent with Creswell's proposition, my research questions operated "under continual review and reformulation" (p.131) during my dissertation. Eventually, I decided on four questions as detailed below.

Research Question One:

What is the value and relevance of understanding the lived experiences of mothers parenting disabled children in Trinidad and Tobago?

This research question examines the value of understanding the lived experiences of mothers raising children with disabilities. Research has found that the experiences of mothers parenting disabled children are different from typical mothers (Al Sayed, Alaskar & Alonazi, 2020), given that they endure a unique set of experiences. I assert from my research that this uniqueness is manifested in the following areas: mothers' expectations versus reality for "normal" child, unpreparedness for the caretaker life journey from diagnosis onward, and mothers' ability to find joy with their children despite the realm of uncertainty following diagnosis. As there is no data that specifically examines this area of study, or as mothers' experiences in raising their disabled children are not regarded as a popular circumstance (Hatun et al., 2016), this research question is pertinent in bridging the gap in knowledge in Trinidad and Tobago and giving mothers a voice (Currie & Szabo, 2019), thereby contributing to an increased understanding of disability. In examining the value and relevance of mothers' experiences, this question also seeks to dispel any misconceptions about disability while highlighting the inefficiencies of social systems in addressing the needs of disabled children in Trinidad and Tobago. As their experiences differ from those of typical mothers (Gona et al., 2018; Harvey & Long, 2020) this question focuses attention on mothers' experiences because they care for a vulnerable section of the population, and their unique efforts should not go unnoticed.

Research Question Two:

How do mothers perceive their roles in caring for disabled children in Trinidad and Tobago?

This question will be examined in two parts. Firstly, I will explore the perceptions that mothers hold of disability, and secondly, I will examine how they view their roles in caring for disabled children. I believe that to analyze the perceptions of mothers in their caregiving roles, it is necessary to establish how they perceive disability. This question will therefore address mothers' understanding of disability by examining the various models of disability as the topic has been understood throughout history. Models can

demonstrate the conceptualization of mothers' thoughts or the way they may construct their realities and derive meaning from living with their disabled children in the Trinidad and Tobago society.

Additionally, this research question will address the way these mothers perceive their caregiving roles. Research indicates that raising disabled children is complex because of the issues surrounding their healthcare, educational and social needs (Currie & Szabo, 2019). This research question will also seek to reveal the complex nature of mothers' attitudes and their motivations for carrying out their excessive caregiving duties. I believe that crucial insights can be gained from understanding mothers' perceptions of their roles and responsibilities in raising their disabled children.

Research Question Three:

How do mothers perceive the government's role in providing educational and support services for disabled children in Trinidad and Tobago?

In the reality of caretakers for children with a disability in Trinidad and Tobago, a primary concern arises in the domain of education. Specifically, access to schooling for disabled children is a crucial consideration as mothers recognize the value in the formal schooling system for the future development of their children (Owusu, Enoch, Mprah & Vampere, 2018; Mack, 2014). These tangible and intangible benefits not only impact the child's development through exposure to socialization, structure, and skill-building but also help to shape the caretaker's psychological well-being given the possibility for their child's employability and eventually, independent living and survival without the caretaker mother. Mothers may turn to the government in fulfilling their supposed role in providing adequate access to formal education.

This research question is also relevant to exploring the role of government in providing additional and updated legislation and offering social support that mothers may need to secure equitable treatment for their children with a disability. Social support can be considered from the perspective of awareness building for families and the wider society. Government establishing and enacting legislation will address several critical areas relating to equality in education and enhanced social services (Charran, 2018; Mack,

2014). This research question can also serve to expose some of the inefficiencies existing in the public system relating to disabilities in Trinidad and Tobago and provide a further understanding of disability. This exposure may highlight the barriers to inclusion and indicate the requirements to ensure greater life chances of success and survival for children with a disability. Additionally, this research question can address what may be needed to build capabilities in the mothers to continue caring for their children in the most optimal way.

Research Question Four:

What lessons can be learned from mothers' perceptions and experiences in raising disabled children in Trinidad and Tobago?

Research Question Four offers a synthesis of the answers to the first three questions. Therefore, this research question will address the potential gains from increased knowledge about the phenomenon under study in this research and the overall understanding of disability from mothers' perspectives.

1.6.2 The Social Constructionist Approach to Understanding Disability

The purpose of this study is to gain a deeper understanding of disability through a critical examination of the perspectives and lived experiences of caregivers raising disabled children. In an attempt to analyze perceptions and experiences, I felt that the use of the social constructionist approach to reality as well as the various models of disability are appropriate lenses through which this can be achieved.

The philosophy of social constructionism denotes that the social construction of reality results from interactions with social and personal influences (Galbin, 2014). Therefore, ontological and epistemological factors can impact the social construction of disability. In other words, the way mothers perceive disability can be as a result of how their realities are constructed, and realities and truths are based on experiences (Clandinin and Connelly, 2000). Disability is a complex phenomenon that cannot be globally defined or understood (Gilson & Depoy, 2000); it may entail cultural understandings and influences, personal orientations and values, and beliefs. Therefore, for each person living with a disability and for their caregivers, particularly mothers in this instance, the meaning they derive out of their experiences will differ.

In their caregiving experiences, it is expected that mothers of disabled children may have to contend or negotiate with proponents of the various models of disability (Crisp, 2002). At diagnosis, they may have to look at the medical model where medical experts' views may be of a pathological nature (Oliver, 2013). At the family and personal level, mothers may have to contend with the religious and charity model as traditions, values, and beliefs surround them. As they care for and educate their children, they may perceive disability from the social and bio-psycho-social models of disability as experiences changes with time (Clandinin and Connelly, 2000). Such a variety of perceptions are underpinned by the notion that there are multiple realities, as mothers interact with people and the social systems in which they live. Experience, therefore, can impact the way mothers perceive and understand disability.

Living with and raising disabled children involves the value judgments placed by society regarding socially constructed norms relating to health and disability (Crisp, 2002; Libert, 2007). Therefore, the way mothers internalize disability can affect the way their perceptions are created or influenced and the way they respond to caring for and educating their disabled children. Understanding the psychology behind their choices and behaviour towards their disabled children is important as it can indicate the kind of interventions that may be needed to enhance the quality of their lives and those of their disabled children. From a social constructionist view, the government can have a better understanding of mothers' lived realities in parenting disabled children. From a national perspective, they can attempt to re-shape societal stigmatizing behaviours and attitudes towards disabled persons.

In disability studies, the literature utilizes many models of disability to explore disability from the medical, social, economic, or political perspectives. The description from these perspectives can have an impact upon conceptualizing the phenomenon of disability as well as comprehending disabled social support (Madi et al., 2019). Models can also offer a paradigm of understanding disability by identifying the causes of disability from different perspectives. In this research, I will examine the medical, social, human rights, charity, economic and bio-psycho-social models of disability, which will be used as a point of analysis in this thesis and will be further explored in Chapter Two. In proceeding, I will provide an outline of the research detailing the aims of the research, followed by a brief description of the methodology and methods.

1.7 Methodology and Methods used in this Study

Narrative as an inquiry method involves the construction, co-construction, and reconstruction versions of oneself, and of significant events of one's life (Clandinin and Connelly, 2000). It is through this storied life that people can understand and communicate the knowledge and interpretation of past and present lives and "speculate about our future" (Barrett & Stauffer, 2009, p.7). Accordingly, owing to the nature of the approach to qualitative inquiry, I chose to use this methodology as it focuses directly on understanding the experiences of the participants. This research adopts a constructivist interpretive approach to inquiry using storytelling as a method of recounting the lived experiences of three mothers who parent children with special needs in Trinidad and Tobago. My positionality is one of an insider/outsider researcher, meaning that in one way, I belong to the group of my participants and in another way, I do not (Unluer, 2012). In this study, I use personal in-depth interviews as the main data gathering procedure to achieve the goal of gathering thick rich descriptions of participants' lives (Geertz, 1973). I choose to use thematic analysis using Clarke and Braun (2014) and Pope, Ziebland & Mays (2000) frameworks for analysis. However, methodology and methods will be further detailed in Chapter Four.

1.8 Chapter Summary

In this Chapter, I introduced the topic of my research which is an investigation into the perceptions and lived experiences of mothers who care for and educate disabled children in Trinidad and Tobago. I began by presenting the background and context for the research, followed by a discussion on Trinidad and Tobago. This discussion examined the geography, a brief history of disability in Trinidad and Tobago, and the structure, and the nature of education for disabled children in Trinidad and Tobago. This was then followed by the significance of the study. Subsequently, I offered a description of my personal background and my motivation for doing this study which was then followed by the statement of the problem. I then presented the aims and purpose of the study which gave a background and a justification for the four research questions as well as a discussion on the theory of social constructionism as well as the models of disability as the lens through which the study is explored. A brief description of the methodology and methods used in the study were then presented. I will now present a structure of the rest of this thesis by outlining the chapters that follow.

Chapter Two presents a critical review of the literature relative to the four research questions. It begins with an introduction followed by a discussion on understanding disability where I examine various definitions and models of disability in greater detail. The Chapter also includes a detailed discussion on the social constructionist theory as well as other discussions relating to the psychological wellbeing of mothers, perceptions of mothers' own roles as well as their perceptions on the role of government. Concepts such as stigma, competence, maternal responsibility, legislation, and schooling are discussed in this Chapter.

In **Chapter Three**, I discuss the methodology and methods or procedures used. Here, I give an overview of the particular research paradigm and research design I chose, justifying its appropriateness for the study. This Chapter also details the various assumptions taken, my role as researcher, a description of the participants, data analysis strategy, and ethical considerations.

Chapter Four presents the findings and a critical analysis of the study. Here, I organize the data into themes while addressing the research questions. I present the findings using three themes followed by a detailed discussion for each theme.

Chapter Five, the final chapter, presents the conclusion and recommendations of my research. In this Chapter, I reiterate the aims and objectives of the study. I also provide synthesized answers to the findings of each of the four research questions. I then give a personal outline of my reflections on this doctoral journey. Further, I discuss the limitations of the research followed by recommendations and further research possibilities. I also discuss the implication of my findings and I conclude with a final comment.

In this Chapter, I focused on the background, context, and setting of the study. Proceeding, I will present a review of the related literature in **Chapter Two**.

2 Chapter Two - Literature Review

2.1 Introduction

This research aims to provide a deeper understanding of disability by examining the lived experiences of three mothers who parent disabled children in Trinidad and Tobago. In this regard, the objectives of this study are to; a) Explore their unique experiences and how these mothers understand disability; and b) Identify how they perceive their role as well as that of the government in caring for and educating disabled children in Trinidad and Tobago. These objectives are intertwined with the four research questions. Hence, this review will address these research questions that I delineated in Chapter One. which are as follows:

1. What is the value and relevance of understanding the lived experiences of mothers parenting disabled children in Trinidad and Tobago?
2. How do mothers perceive their roles in caring for disabled children in Trinidad and Tobago?
3. How do mothers perceive the governments' role in providing educational and support services for disabled children in Trinidad and Tobago?
4. What lessons can be learned from mothers' perceptions and experiences in raising disabled children in Trinidad and Tobago?

I begin with an analysis of some of the definitions of disability as well as a critical exploration of the models of disability. I also explore the theory of social constructionism as it relates to the social model of disability. Subsequently, I present literature examining the value of understanding mothers' experiences as the primary caregiver for their disabled children. I also expound on the factors influencing mothers' perceptions of their caregiver role. Following this, I refer to research regarding factors influencing mothers' perceptions of the government's role in educating and caring for disabled children.

A review of literature entails a comprehensive examination of current research relevant to a field of study. It includes a presentation, and critical evaluation of existing research, theories and evidence, as well as one's own assessment, and discussion of the content being explored. One of the objectives of doing a review of literature is to uncover the knowledge based on the current body of available literature. This identification can

provide an avenue to increase awareness or broaden understanding in an area of study. In this literature review, I will explore the gap in the literature as it relates to perceptions of disability with a focus on the Trinidad and Tobago context, aligning it to models of disability and the theory of social constructionism.

The limited literature on disability continues to pose a challenge in the attempt to understand or evaluate the perceptions towards disabled persons (Munyi, 2012). Such perceptions generally have an impact upon families of disabled persons (Mokhtari & Abootorabi, 2019). Moreover, as mothers are the primary caregivers for their children (Harvey, 2015; Zulfia & Allenidekania, 2020; Kim & Hwang, 2019), I believe that research on the meaning of mothers' unique experiences and perceptions about their roles in raising their children with a disability is very important. Mothers' stories can help us to better understand the human aspect of parenting children with a disability (Kim, 2016, p. 118) from the perspective of a primary caregiver.

A general problem is that in Trinidad & Tobago there is a dearth of literature that directly addresses the care and education of children living with a disability (Charran, 2018; Parey, 2020). The precise problem that this research seeks to address is the lack of understanding of the experiences of mothers raising children with a disability in Trinidad and Tobago and the way they and others in society perceive disability. A potential consequence of disability being an under-explored area is that it creates or enhances the taboo around treating with disability. This taboo can, in turn, produce further unwanted outcomes at the social level. These consequences may include the unfair treatment of persons with a disability, which can be exacerbated by factors such as low socioeconomic status, scarcity of government programs, or even lack of political will in developing countries to address the needs and rights of disabled persons (Groce, Kett, Lang & Trani, 2011). Moreover, since research in the area of disability is lacking in Trinidad and Tobago, this seminal review will provide an opportunity to understand how mothers of disabled children draw meaning from their daily lives (Kim, 2019).

The various roles mothers assume in caring for and educating their disabled children can have specific relevance in the Caribbean context and in Trinidad and Tobago. This can be particularly helpful given the stigmatizing beliefs about childhood disability (Angermeyer, Matschinger, Link & Schomerus, 2014) as well as the de-prioritization of

disability in developing societies (Charran, 2018; Conrad, et al., 2010; Roopnarine, Logie, Davidson, Krishnakumar, & Narine, 2015). Maternal perceptions can provide information on how to identify disabling factors caused by societal beliefs about disability, and how this affects legislation, education, and the provision of social services (Roopnarine et al., 2015). An understanding of these perceptions can be used by educators, social service providers, clinicians, other mothers, as well as the government in securing a level of protection and assistance for mothers' psychological wellbeing. Mothers are the ones who have primary knowledge (pre-natal and post-natal) about their children's development and as such, working with them can provide a better understanding of the developmental needs of children with a disability.

For the purpose of this review, I seek to provide a context around understanding disability in relation to the research questions listed above. To this end, I first examine critically the various definitions of disability in addition to providing an evaluation of the different models of disability.

2.2 Understanding Disability – Definitions and Models

Defining disability is a complex and evolving matter (WHO, 2011; Gilson & Depoy, 2000). The term “disability” includes a wide range and degree of conditions. A disability could be present at birth, caused by an accident, or advanced over time. Hence there are many ways to conceptualize disability. Some of the ways can be through definitions of disability, through models of disabilities, or one's own experiences. However, in explaining disability, one has to be mindful that there is no universal definition of disability (WHO, 2011; Groce, Kett, Lang & Trani, 2011; Shakespeare, 2002) and therefore disability is subject to interpretation.

2.2.1 Definitions of Disability

The World Health Organization (WHO) is an influential and leading body that advises on health and disability concerns for the world. The International Classification of Functioning, Disability, and Health, known as ICF, is the WHO's framework for disability and health (Leonardi, Bickenbach, Ustun, Kostanjsek & Chatterji, 2006), and offers a definition of disability. In the 2011 World Report on Disability, the WHO stated that the ICF described disability as:

“the umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO, 2011, p. 4).

According to the WHO (2011), the ICF understands that functioning, (which are all bodily functions, activities, and participation of an individual) and disability interact dynamically where it considers an individual’s health conditions and an individual’s personal and environmental factors. The WHO, therefore suggests that the degree to which a person with a disability can function is determined by the individual’s medical health factors, combined with personal and social factors.

The definition provided by the ICF is thorough (Reitief & Letsosa, 2018) and worthy of consideration. It encompasses both the medical conditions that may render an individual unable to function optimally and it also has tenets of the social model of disability where it considers the restrictions and barriers created by social structures that disable the individual. An understanding of both the health and the environmental features of disability permits an exploration of various kinds of interventions that may be necessary to improve the participation of all disabled people (Leonardi et al., 2006). The definition of the ICF is an improvement to the definition of disability given by the United Nations Draft Convention on the Rights of Persons with Disabilities in 2006. In Article One of the 2006 document, the definition stated, that “disabled persons include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 4). A criticism of this definition is that it only refers to persons who have long-term impairments and do not consider short-term illness that may render individuals disabled (Leonardi et al., 2006). Such a definition can also focus people’s or the state’s attention only on the severely disabled individuals whilst ignoring other types of disabilities that are not noticeably severe, or that are hidden, such as cognitive or intellectual disabilities.

The thoroughness of the ICF’s current definition is enshrined in its recognition of a) environmental factors such as products and technology; the natural and built environment; support and relationships; attitudes; and services, systems, and policies; and b) personal factors, such as motivation and self-esteem, or a person’s capacity to perform activities (WHO, 2011). The definition and language used in the ICF’s definition

universally encapsulate all human functioning and regard disability as a continuum rather than classifying disabled persons as a standalone group (WHO, 2011). The WHO denotes that the ICF definition can be used by governments in crafting appropriate policies for research related to health, medicine, welfare, and educational services.

In Trinidad and Tobago, the National Policy Document on Persons with Disabilities (2018), produced by the country's Ministry of Social Development and Family Services, defines disability as: "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal" (p. viii). This definition is extracted from an earlier manual by the WHO (1980) entitled 'International Classification of Impairments, Disabilities, and Handicaps'. In the current disability discourse, definitions containing language terms such as 'handicap' and 'normal' can be considered stigmatizing when referring to persons with a disability or with multiple disabilities. Hence the Ministry has not adopted the ICF's recent definition in its policy document. As a result, the current definition is outdated as used in the Trinidad and Tobago policy and does not account for all the physical and mental functional aspects of disabled persons or the intertwining of the health and environmental aspects. The language used still focuses on the idea of normalcy that suggests a comparison to non-disabled persons and which can influence perceptions of and the extent to which people prioritize disabled persons in Trinidad and Tobago. As Donoghue (2010) and Mokhtari, & Abootorabi (2019) both contend, the comparison to normal which aligns to the medicalization of disability does not appeal to the sensitivity towards an already marginalized population.

In gauging what can be done to improve the lives of all disabled persons including children, the definition provided by the ICF would be most appropriate in addressing most of the concerns or needs that the disabled population may encounter throughout their lives. According to Retief and Letsosa (2019), one of the positive aspects of this definition is that it leaves room for improvement or changes. The ICF definition of disability incorporates tenets from both the social model and the medical models of disability. Apart from definitions, models of disability, which will be explored in greater detail in the following section, can also provide an avenue to comprehend disability. The models themselves may contain their own nuances in understanding disability.

2.2.2 *Models of Disability*

There are a variety of ways to understand disability and each method can produce profoundly different implications and effects on the lives of children with a disability and their caregivers. These ways of understanding are exemplified in the various models of disability that exist. Models of disability can be thought of as tools for defining impairment and which can be used by the government and society to devise strategies for catering to the needs of disabled people (Smith & Bundon, 2018; WHO, 2011). Models can also be used as a framework to gain a more in-depth understanding of disability issues, as well as the perspective held by those creating and applying the models. For example, the way the government perceives disability through the lens of a particular model can have implications on the way they prioritize disability (Smith & Bundon, 2018). This prioritization can be viewed through legislation and the social and educational programmes for children with a disability and their families. Understanding disability can be problematic as there is no consensus on its definition (WHO, 2011) neither is there any absolute correct model that encapsulates all aspects of disability (Smith & Bundon, 2018). In other words, Smart (2009) concludes that each model is *reductionistic* insofar as they each emphasize certain aspects of disability, but not all aspects.

In the burgeoning field of disability, the various models of disability can reveal how society provides or limits access to work, education, goods, services, economic influence, and political power for disabled persons. For example, if a model sees disabled persons as dependent upon society, this can result in paternalism, segregation, and discrimination (Gilson & Depoy, 2000; Anastasiou & Kauffman, 2011). If a model treats persons with a disability as customers of what society offers, then it will lead to choice, inclusion, equal access, empowerment, and equality of human rights (Gilson & Depoy, 2000; Degener, 2014). Furthermore, models can provide an insight into the way mothers also conceptualize disability based on their experiences in raising a child with a disability (Landsman, 2005). As I examine the different models of disability, I will show how models can influence perceptions (Retief & Letšosa, 2018) including those of government, wider society, and mothers of disabled children. I will present the development of disability models as this will provide a context of how perceptions were formed, and how they endured despite new and emerging developments in disability studies. In proceeding, this review will examine the moral/religious or charitable models

of disability as well as the social, medical, human rights, economic and bio-psycho-social models of disability.

2.2.3 *The Moral Religious / Charity Model Of Disability*

Retief & Letšosa (2018), cited Pardeck & Murphy (2012) as saying that the moral/religious model of disability is possibly the oldest model of disability supported by and possibly emanated from several religious traditions, such as Christianity and Judaism. This model denotes that disability is regarded as a punishment from God when a person with a disability commits a sin. Another view is that when a child is born with a disability, it represents a consequence of the sins committed by the parents (Henderson & Bryan, 2011), or more specifically, those of the mother. This is also true in the Hindu tradition that embraces the belief of Karma, meaning payment or punishment for one's deeds. As some authors suggest (Heiman, 2002; Kamenopoulou & Dukpa, 2018; Lalvani, 2011), when a child is born impaired, the punishment for the mother is having to produce and raise a less than "perfect" child.

Landsman (2005) also theorizes that mothers who parent disabled children are placed in a "moral category" where they are either blamed for having an "imperfect" child or are uplifted to the role of being gifted by being handpicked by God to mother a special child. According to Retief & Letšosa (2018), this God-given opportunity to parent children with a disability is a conception that is almost salvific as it can be a test of faith, a blessing, or a chance for mothers to redeem themselves through resilience and piety. Such beliefs can influence the way people perceive mothers who parent disabled children. For example, people's perceptions can hold mothers solely responsible for a child's impairment as well as project blame unto them for producing a so-called "blemished" child. Moreover, as Munyi (2012) denotes the perceptions of wider society or even family members can exert pressure on the mental state of mothers while exempting themselves from any responsibility to assist mothers in their care burden for disabled children.

The religious or moral model of disability is also referred to as the charity model of disability, and understandably so. According to the charity model, disabled persons are regarded as victims of circumstance and should be pitied (Retief & Letsos, 2018; Jackson, 2018). Jackson (2018) in a study on the built environment and accessibility for persons with a disability purported that this model is characterized by the perception that disabled

persons require attention and need to be taken care of, as they are “vulnerable others” (p.3). Jackson found that the economic and social order must also be protected from disabled persons as they can be perceived as deviant. To this end, he argued that children with a disability are included in the group of vulnerable people and are historically placed in institutional care settings, both geographically and culturally away from the public’s immediate eyes. Social isolation and exclusion are, in this context, likely consequences of the charity model of disability.

The moral, religious, or charity model, although not as pervasive as in premodern times, continues to influence the perceptions of disability and the treatment of persons with a disability through its underlying philosophy. My view is that since this model can be traced back to biblical times (for those who believe in Christianity) when Christ healed the sick and made the disabled walk, disability as conceived from a theological perspective is something that could be healed and cured (Bennett & Volpe, 2018). Further, as medicine became more advanced, the notion of curing the disabled remained the foundation upon which the medical model of disability was built. It may appear as if doctors were considered almost sacredly powerful as they possess the ability or the knowledge to ‘cure’ illness. Hence the medical model of disability seems like a natural progression from the religious model. It is not surprising that despite advances in disability studies, as evident by new models, the charitable outlook and medicalized beliefs about disability remain rooted in the minds of many people (Donoghue, 2003) including mothers who parent children with a disability.

2.2.4 *The Medical Model of Disability*

From the mid-1800s onward, the medical or individual model later termed the biomedical model of disability, slowly began to replace the moral or religious model as there were significant advances in the medical field (Retief & Letšosa, 2018). These conditions underpin what Oliver calls the *personal tragedy model* since it describes disability in a negative light, almost as a disease that afflicts unfortunate persons in society (Jackson, 2018; Oliver, 1990; Retief & Letosa, 2018). Singh & Chopra (2020) also agreed that disability was traditionally viewed from a medical perspective. Research on the medical model of disability considers disability as a problem located within the body or mind of an individual and defines disability from a pathological perspective (Asa, Fauk,

Ward & Mwanri, 2020; Christensen-Strynø, 2016; Collins & Coughlan, 2016; Landsman, 2005; Oliver, 1990a; 2013b; Riddle, 2020; Scotch, 2000). The central tenets of this model are, firstly, that a person's impairment can be diagnosed or cured by medicine or medical technology, and secondly, that such interventions can only come from medical experts (Jackson, 2018; Levitt, 2017). In the medical model, disability can be measured, classified, quantified, and standardized (Smart, 2009). Given its influential doctrine for over a century, the medical model has succeeded in limiting the views of more recent models of disability. Landsman notes that even mothers who object to certain kinds of diagnosis and treatment of their child's disability by medical experts, still uphold their beliefs in the medical model without even realizing it, trying to make their children reach a functional level of being normal in society (Landsman, 2005).

Smart (2009) refers to the medical model as the biomedical model and notes a few of its limitations. One such criticism is that it creates a power differential between the medical experts and individuals with the disability. This inherent power is where the model creates a type of prejudice by influencing doctors and the public to think about disability as being more a concern of medical practitioners (Smart, 2009). The medical model supports the belief that illness and disability are the same, and as doctors are trained to diagnose, treat and cure diseases, they tend to *medicalize* disability by *normalizing* disabled persons (Levitt, 2017). The perception that disabled persons can be cured of their disablement and become *normal* is implied in the 1980 definition by the WHO mentioned above. To a certain extent, the medical model places much of the responsibility of caring for disabled persons in the hands of medical doctors and relieves society of its role in creating an enabling environment for disabled persons.

Following this trend of thought, another criticism is that the medical or biomedical model views disability as an "individual inferiority" as it legitimizes discrimination on a societal level (Smart, 2009; Oliver, 2013). For the last century, this model (Scotch, 2000) has dominated the way the public's perceptions and attitudes towards disability are shaped, indicating that there has not been much discussion by *ordinary people* over the years (Singh & Chopra, 2020). Smart (2009) contends that this lack of open discussion and resultant lack of knowledge contributes to an unrealistic fear of becoming or being disabled, although disability is a common, widespread experience. It may be noteworthy to indicate here and considering the larger context of this research, that such "ordinary

people” include mothers of disabled children and their subjective experiences, as underscored by the social model of disability.

2.2.5 *The Social Model of Disability and Social Constructionism*

Before delving into the social model of disability, I found it necessary to discuss the social constructionism approach to reality. From a historical perspective, social constructionism is a theoretical orientation that underpins various disciplines which includes phenomenological psychology, social history, hermeneutics, and social psychology (Burr, 2003). Earlier writing by philosophers Immanuel Kant and Karl Marx also contained remarks from a constructionist perspective (Brewer, Brueggemann, Hetrick & Yergeau, 2012; Galbin, 2014). However, from the 1960s other groups began to accept the phenomenon known as *constructionism* (Brewer et al., 2012). Therefore, although the term social constructionism is relatively new in the discipline of psychology or disability studies, the thinking has been around for some time and is where the social model of disability takes its roots. Galbin (2014) defines social constructionism as:

“the social construction of reality...that examines the development jointly constructed understanding of the world. Social constructionism may be defined as a perspective which believes that a great deal of human life exists as it does due to social and interpersonal influences.” (p. 82).

The philosophy of social constructionism is opposed to that of positivism or empiricism which views reality as predictable, standardized, and measurable (Burr, 2003; Creswell, 2013).

Social constructionism purports that the different kinds of knowledge one attains are attributed to one’s unique cultural, historical, and social experiences. This means that knowledge is subjected to experiences and may not represent the exact truth, as everyone’s experiences differ (Galbin, 2003). As such, being raised in society to think about disability from a pathological perspective is more cultural and traditional than the actual reality about disability. It is not surprising that given that the medical model of disability has been around for over ten decades, its views on disability will influence the perceptions of many people including mothers who parent disabled children.

2.2.6 Knowledge Creation

The social constructionist theoretical orientation regards knowledge as created from interactions with one another in their social settings. The most basic form of communication among human beings is language since people in their everyday lives interact and reconstruct their individual realities by sharing versions of knowledge (Burr, 2003). Our knowledge of what constitutes reality is also entrenched in the institutional fabric of society (Galbin, 2014). When children are born, they come into a world that already has a conceptual framework that provides a platform to make sense and meaning out of concepts and categories of things (Burr, 2003). This meaning-making is done through the use of language; therefore, language influences one's thinking. According to Burr, language is not just an "expression of thoughts but a pre-condition for it" (p. 8). The language used for various models of disability will also impact the way people interact and work together or construct their worldviews. Moreover, it is the way knowledge is created through the language used by various models of disability in different societies that we can reconstruct our worldviews in thinking about disability.

Burr mentioned that knowledge can then be considered a social *action* as each construction brings a "different kind of action from human beings" and different "versions of our own reality" (p. 6). Therefore, as Burr (2003) contends, there is no "objective fact" that "all knowledge is derived from looking at the world from some perspective or other" (p. 6) and from interacting and communicating with each other. In the context of models of disability, the way one perceives disability becomes their "truth" as it aligns to their cultural beliefs and ways of thinking (Burr, 2002; Galbin, 2014). For example, a child with a disability is pathologized by locating the "problem" within the child (medical model of disability), but social constructionism examines the degree to which the disability is a construction that emerges through interactions with parents, doctors, teachers, and others in society (social model of disability). If the concept of disability is seen from the social constructionist perspective, then people's bodies are not characteristically imperfect. This thinking is aligned to the social model of disability. By its tenets, therefore, the social model of disability is based upon the principles of the social constructionism approach to reality which be discussed in the following section.

2.2.7 *The Social Model of Disability*

The social model of disability emerged from the British disability movement developed in the 1970s by activists in the Union of the Physically Impaired Against Segregation (UPIAS) (Shakespeare & Watson, 2002; Oliver, 2013). According to this model which was also referred to as the political model or the minority model (Shakespeare & Watson, 2002), it is the society that disables physically impaired people. Disability is regarded as something that is imposed on top of impairments as it results in social isolation and oppression (Shakespeare & Watson, 2002). The social model of disability is a phrase coined by Mike Oliver (Oliver, 2013; Owens, 2015) that locates the impairments in disabled persons within the society that discriminates against them and not within the person's body itself (Oliver, 2013).

According to Shakespeare and Watson (2002), this model is significant in many respects: it recognizes disabled people as an oppressed group, it differentiates impairments from oppression, and it defines disability as social oppression. As a result, at the very core of this social model of disability is the belief that disability is a socially constructed phenomenon. This view is confirmed by the WHO (2011) when it stated that disability is an evolving concept. The social dimension of disability emphasises a distinction between impairment and disability; impairment being the lack of bodily parts or illness directly related to the individual which can cause one to be disabled as well (Shakespeare & Watson, 2002), while disability evokes the notion of restrictions and barriers created by the society that limit the individual from full participation (Retief & Letsosa, 2018; Oliver, 2013). From this perspective, according to the UPIAS (1976), disability is viewed as a socially constructed hindrance, which is imposed upon disabled persons and which constitutes social oppression.

The social model has also played a critical role in the development of disability policies for disabled persons both at the national and international levels. The WHO (2011), for example, used the social model as one of its bases for developing the ICF's conceptual framework on disability. Governments reference this international framework as a guideline to develop their policies at a national level. The language or terminology encapsulated in this model is also significant as it calls out the oppressive nature of

society. Some researchers and theorists argue that the term “people with disabilities” is directly linked to those ideas fundamental within the medical model of disability (Shakespeare, 2010). As a result, social researchers think that the term “disabled people” or “disabled persons” should be used as it reflects more distinctly, the societal oppression that people with impairments face (Isgro, 2015; Landsman, 2005; Retief & Letšosa, 2018; Oliver, 2013).

By saying that society disables disabled persons, the social model aligns itself to a political nature that emphasizes the need for governments to reduce the restrictions created by structural and attitudinal barriers in society which can be viewed as oppressors. Thus, disability policies may have to address these concerns in their policies and legislations as seen in the international Conventions held by the United Nations and the WHO (2011). Shakespeare and Watson (2002) share Riddle’s views that the social model “enabled the identification of a political strategy, namely barrier removal” (p. 5). Hence, in this model, the removal of societal barriers is given priority and therefore promotes a greater degree of inclusion for disabled persons (Oliver, 2013). Regarding the social model of disability, Garland Thompson (2011) spoke about the relationship between disability and disabled persons where the disabled is a “misfit” in society. She succinctly states that “disability oppression ... emanates from prejudicial attitudes that are given form in the world through architectural barriers, exclusionary institutions, and the unequal distribution and access to resources” (p. 591). This remark can relate to the theory of social constructionism as discussed above, where the impairment of the body is relative to the barriers existing in a society that cause one to be disabled.

The social model seems to be the model that empowers and mobilizes disabled persons, possibly because it reflects the actual experiences of their everyday lives (Riddle, 2020; Shakespeare, 2010). I justify my choice to concentrate on the social model of disability in this research as I seek to understand the perceptions and lived experiences of the mothers in caring for their disabled children. Riddle (2020) also contends that compared to the medical model of disability, the social model is superior not only for its focus on political, social, legal, and attitudinal experiences but also for its ontological ones. According to Riddle, the social model, therefore, corresponds more precisely to reality which acknowledges that disability carries a more robust set of social circumstances that positively impact the lives of people with a disability. Similarly,

Shakespeare (2010) agrees with Riddle's view from the perspective of the freedom of disabled persons; he upholds that the removal of barriers creates a kind of liberation for disabled persons.

Another benefit of the social model of disability according to Levitt (2017) is that it has changed "society's relationship with disabled people and its understanding of disability" (p. 590). For over a century the medical model had dominated the understanding of disability which, to a great extent, resulted in discriminating treatment towards disabled persons. With the social model, there is a new emphasis on persons with a disability where society and government now have to adjust policies and influence perceptions orienting disabled persons as more "human" and deserving of equal treatment (Oliver, 2013, 1990; Van Trigt, Kool & Schippers, 2016). Aligning this research to the social model of disability identifies the barriers that limit mothers from optimally caring for their disabled children that the later sections will discuss. If government and society look closely at this theory, they may be more inclined, to aggressively change perceptions towards disabled persons and their caregivers. They may seek more inclusive strategies by making provisions for the removal of social barriers by considering the accessibility and the built environment (Jackson, 2018) and enacting legislation to assist all disabled individuals (Charran, 2018).

While there are arguments for the social model of disability, there are several points of critique that have been levelled against the social approach. Oliver's (2013) theory of the social model was met with criticism from the onset. One is that the social model does not consider impairment within the model itself (Oliver, 2013; Shakespeare, 2010); that is, although there may be social barriers to inclusivity, some persons with impairments will still be disabled even with the removal of societal barriers. For example, a visually impaired person will never be able to drive a car, regardless of which barriers are removed. Their impairment will render him/her incapable to drive unless the person regains their sight. Another criticism is that the social model does not take into account the nuances of disabled people but rather presents them as a single group, which discounts the complexity of people's lives given the existence of race, age, gender, and sexuality factors (Oliver, 2013; Owens 2015). However, Oliver restated his purpose that the social model originally intended to be "a tool to improve people's lives" referring to disabled persons (Oliver, 2013). I agree with Oliver's original stance. The underpinnings of the

social model are valuable in helping to understand disability through the lives of caregivers including mothers of disabled children. Gaining an insider perspective of how they view disability can assist the government and wider society to realize that they should give greater priority to both children and adults who are disabled.

Other research, such as by Tom Shakespeare (2002), proposed that there needs to be a new social theory around disability contending that at the time the social model was developed, it was well suited and has served its purpose excellently. However, Shakespeare believed that now, in the twenty-first century, the social model is an “inadequate grounding for a social theory” (p. 29). He maintained that all individuals are impaired in some way as no one is perfect; we are all mortals and will die of some ailment or cause (Shakespeare, 2002). While Shakespeare’s argument may be valid, one should consider that some ailments are more “accepted” by society than others possibly because of the number of persons living with the ailment. Also, in many cases, medical cures and treatments exist for some of these ailments or impairments. Other arguments by Berghs et al. (2016) for example, offer that new developments are required from the social model, and as Levitt postulates, the social model can be “re-invigorated” to serve disabled persons in the current time in which we live (Levitt, 2017). Levitt was suggesting that the scope of the social model should be expanded in order to see the conditions of countries to which the model can be applied (eg. level of poverty) or to evaluate the relationship of the social model to other models of disability.

Despite the criticisms about the social model of disability, the significance of this model and its contribution to understanding the realities of people living with a disability and their caregiver’s daily experiences is invaluable. The social model gives insight into the experiences of the disabled population (Riddle, 2018) because it frames disability in an environmental context which other models failed to accomplish. For this research, the social model provides a strong framework for understanding and analyzing the life experiences from the perspectives of mothers who parent children with a disability (Green, 2007; Landsman, 2005). Furthermore, its alignment to the social constructionist approach provides a basis for understanding the “tensions of self and social constructed identities” that one may have from competing views of the medical and social models of disability (Crisp, 2002). Additionally, the social model of disability provides a framework

for international and national organizations to craft more inclusive policies for their disabled population.

Other Models

In the following discussion, I will look briefly at the other models of disability that are more recent in development. These models bear close association to the social model but with some distinctions. For this review, I will explore the human rights model, the economic model, and the bio-psycho-social model of disability.

2.2.8 The Human Rights Model of Disability

This model is grounded in the philosophy of the social model of disability. Its basic principles denote that all persons including children with a disability have an equal right to living equitably as others in society regarding health, education, employment, and independent living (Degener, 2014; CRPD, 2015). According to Degener (2014), although reference was made to the social model of disability when the CRPD was being drawn up, the human rights model goes beyond in six distinct ways. These are itemized in Table 1 below, which is adapted from Degener, 2014 (p. 6-26).

Table 1 – Comparison of the Human Rights Model and the Social Model of Disability

HUMAN RIGHTS MODEL	SOCIAL MODEL
Suggests impairment does not hinder human rights capacity	Explains disability
Includes first and second generation human rights (civil, political, economic, social, cultural rights)	Supports anti-discrimination policy civil rights reforms
Values impairment as part of human diversity	Neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life and early death due to impairment, and dependency
Acknowledges identity issues	Neglects identity politics as a valuable component of disability policy
Allows for assessment of prevention policy	Critical of prevention policy
Strives for social justice (pages 6-28)	Explains the close link between poverty and disability

Concerning the six items highlighted above, the human rights model therefore underscores human dignity of disabled persons; various rights; recognises social justice

issues; caters for minority and cultural identification; recognises the importance of appropriate health prevention policies for disabled persons; suggests constructive strategies for improving the quality of life of disabled persons especially those who live in poverty (Reitief & Letsosa, 2018). One justification for using this model is that the WHO in 2011 recognized the importance of human rights in its World Report on Disability and highlighted that disabled persons experience inequalities, are subject to violations of dignity, or are denied autonomy. In this regard, the bio-psycho-social model proposed by the WHO contains the need for human rights recognition.

While the social model represents a paradigm shift from the medical model, this new human rights model also builds upon the social model as the way forward for disabled persons. Additionally, some people see it as an improvement to the social model (Degener, 2014). Regarding children with a disability, there is an appropriate connection to the Convention of the Rights of the Child (WHO, 2011). In the context of Trinidad and Tobago, this model warrants some consideration given the country's lack of legislation on disability rights (Charran, 2018). However, as Degener (2014) points out, the implementation of this model is yet to be fully realized globally as it is possibly still not thoroughly understood.

2.2.9 *The Bio-psycho-social Model of Disability*

In the section above where I discussed definitions, I offer an explanation of the ICF's definition of disability which states that disability encompasses a mixture of impairments, activity limitations, and participation restrictions (WHO, 2011). The bio-psycho-social model of disability is a reflection of that definition. This model concentrates on environmental factors as being one of the causes that disables a person. The ICF categorizes the human functioning problem into three interconnected areas: impairments (bodily function), activity limitations (problems in performing activities), and participation restrictions (problems regarding involvement in life) (WHO, 2011, p. 5). The ICF explains that disability results from difficulties faced in any of these areas of functioning. The ICF uses generic language to not make a clear demarcation between the kinds of disabilities or the causes of disability. According to this model, disability emanates from the interaction of "health conditions with contextual factors" (WHO, 2011, p. 5) which consists of environmental and personal factors. Much of what was

mentioned in the definition given by the WHO earlier is what embodies the bio-psycho-social model of disability.

According to the ICF (WHO, 2011), the three distinguishing features of the model is the concentration on environmental factors, personal factors, and a person's capacities to perform actions. A commendable feature of this model is the forging of the two most prominent models of disabilities that continues to dominate current discourses on disability, these are the social and medical models. The WHO also acknowledges the utility of the model, saying that it can be used for "research, surveillance, and reporting" (WHO, 2011, p. 5). An examination of these features and the adoption of the model by the government can create a new way of understanding disability. If legislation is put in place that considers the guiding principles of this model, then it may begin the process of changing perceptions of disability. The model rests the responsibility squarely on the shoulders of the government to dismantle barriers to inclusion and increase participation for disabled persons. However, as the WHO (2011) notes, policy-makers and service providers may need "thresholds to be set for impairment severity, activity limitations, or participation restriction" (p. 5) in implementing this model.

2.2.10 The Economic Model of Disability

The economic model of disability views disability as a person's inability to participate in work. According to Retief, & Letšosa (2018), this model focuses on the "disabling effects of an impairment" (p.6) on a person's capacity to carry out labour and employment activities. These authors contend that although the economic model purports that it is concerned about respect and civil rights, such concerns are subordinate to the model's valuation of a disabled person's ability to work and contribute to the economy. However, the uses of this model are typically favoured by governments, who craft their economic policies in order to lower costs and maximize benefits (Jordan 2008 as cited by Retief & Letsosa, 2018). An additional consideration can be given to caregivers of children with a disability. In many instances, mothers cannot participate in work because of their intense care burden (Gilson & Depoy, 2000; Anastasiou & Kauffman, 2011). Flexibility in work arrangements for caregivers of a disabled child or adult can be a consideration by employers as it represents an equal opportunity to earn a living and

support their families. However, such consideration can only be promoted by awareness building and government initiatives.

Retief and Letsosa (2018) put forward one of the criticisms of the economic model of disability. They said that the model frames disability almost solely in terms of cost-benefit analysis, disregarding other important human factors. Hence the application of this model can promote the perception that disabled persons cannot be productive workers or who may be seen more like a liability to companies or government (Saleh & Bruyère, 2018). The model has implications that disabled persons are supposed to be on welfare which may be a concern for the government. Employers may even think that special provisions may have to be made for disabled persons especially if they weigh hiring a disabled individual against the expected degree of productivity from that person. The implication of this model for mothers of disabled children is that their children attaining employability age may find it difficult to get a job and earn an income. As a result of this welfare perception or the assumed inability to work (Baker et al., 2018), the chance of equitable and independent living may be limited for children with a disability reaching employment age. In this way, the economic model relates to that of the charity model where employing disabled persons seems more like a charitable act.

In this section, I presented the definitions of disability as well as the various models of disability. Whilst I discussed the various models and their influence on perceptions of disability, I narrowed my focus on the charity, social and medical models as I believe that these models have a greater influence on the perceptions of mothers in caring for their disabled children. From an analysis of the ICF's bio-psycho-social model of disability, one should possibly view models, not as a set of exclusive options with one superior to or substituting previous sets. The development of the models and their popularity provides a continuum on changing social attitudes to disability over time as models develop as society changes. The ICF model is a prime example of this where it combines two models to encapsulate a wider range of considerations for disabled persons. Given this degree of understanding, an objective should be to use the various models of disability in a way that will question discriminatory perceptions and empower disabled persons, as well as those who care for them, thereby giving them equal rights along with their fellow citizens. In moving forward these models will serve as a basis for discussion of the literature regarding the three research questions.

2.3 *The Value and Relevance of the Mothers' Experiences*

In this section of the literature review, I will address the first research question of this study, which examines mothers' lived personal and social experiences of parenting disabled children in Trinidad and Tobago. Specifically, I draw on several international sources of research while demonstrating the value and relevance of understanding the caregiver's experience. Parenting a child with a developmental or other disability is a huge responsibility. Although caregiving is a customary role in parenting any child, caring for a child with long-term cognitive and functional limitations can present a new set of challenges and health effects on the primary caregiver of both a physical and psychological nature (Green, 2007; Lalvani, 2011). In reviewing these caregiving demands and while seeking to better understand the coping strategies from the caregiver's side, the literature appears to be limited by a lack of adherence to a specific theoretical framework (Harvey, 2020). Harvey and Long (2020) note that mothers parenting disabled children endure a unique set of experiences as do their children. These authors suggest that mothers' experiences should be distinct and not grouped with all disabled people without taking into account the specific nature of their "sufferings and exclusions" (p. 462). According to Harvey and Long, a more profound understanding of mothers' experiences can provide insight into what may be required to enhance the lives of disabled children and their parents who face stigma and isolation.

Part of the unique experiences of mothers of disabled children is that they experience greater levels of psychological stress and trauma than mothers who parent children without a disability (Bourke-Taylor, Howie & Law, 2010). Bourke-Taylor et al. (2010) suggest that mothers' caregiving role is similar to that of a full-time occupation or caretaking career which is an area of study that is limited in the research. Mothers must fulfill this caregiving duty, in the face of discrimination and *otherness* which is distinct from mothers raising a child under normal circumstances. Lalvani (2011) also notes an interesting concept where she referred to mothers of disabled children as "m(others)" (p. 276). Contending with Tuhiwai-Smith (2012), Lalvani suggests that these mothers are *othered* to the degree that they have been ostracized from the normal activities that individuals and wider society enjoy (Zulfia & Allenidekania, 2020). Being *othered* according to Carroll (2016) indicates claims of superiority "within a stigma-phobic, normative world view claiming others as external and inferior" (p. 253). An inquiry into the experiences of mothers who parent children with a disability in Trinidad and Tobago

can assist researchers to appreciate the complex nature of caregiving that mothers live through daily with their disabled children (Goodley & Tregaskis, 2006). Yoosefi-Iebni, Ziapour, Khosravi & Kandi (2020) observe that having disabled children poses many problems and tensions for all family members, but mothers are the ones most at risk since their relationships with their children have a stronger emotional bond. In carrying out their caregiver role, mothers must first deal with the trauma of diagnosis of their child's disability.

2.3.1 Dealing with Diagnosis

Most parents imagine a "perfect" baby when expecting children (Landsman, 2009; Dehghan, Dalvandi, Rassafiani, Hosseini, Dalvand & Baptiste, 2015). When a child is diagnosed with a disability, it signals the onset of a life that was not envisaged by parents. According to Runswick-Cole and Ryan (2019) "having a disabled child is typically an unfamiliar experience and families start from scratch on an unexpected journey" (p. 1136). According to Russel (2003), expectations are "subjective predictions about the future" and are based on a solid foundation "associated with a high degree of certainty" (p.145). Russel further contends that expectations come from a person's social environment and their interactions, and affect their beliefs, knowledge, and experiences. Hence a person's expectations are based on their culture, traditions, and values. A mother having a child with a disability may have to review these expectations in light of their unpreparedness of having a child with a disability and "gains a greater understanding of their personal experiences" (Russel, 2003, p.145).

The psychological state experienced by mothers from the unexpected event of parenting disabled children, in general, is one of loss or death of the ideal or desired child (Barbosa, Chaud & Gomes, 2008; Harvey & Long, 2020) and one of uncertainty as Russel (2003) purported. According to Landsman (2009) words such as "normal" or "perfect" used to describe a newborn's condition carry a huge emotional burden "and their use is rightfully offensive to many people" (p. 11). Mothers whose children are born or diagnosed with a disability must confront and bear this diagnosis, and in many cases, they are not prepared for such a life-altering task (Russel, 2003). I recall from my experience when my youngest child was born, the nurse counted to see whether he had ten fingers and ten toes and if he was able to cry. This kind of validation of the perfect body of the child seemed to me, as I concur with Landsman (2009) to be the gold standard for

measuring normalness or probably *accuracy* as having “zero defects”. Such perception tends to objectify children who have a disability. Hence, it is this accompanying sense of relief that the “privileged parent” experiences that are absent from the realities of “m(others)” who have to care for their disabled children.

Deriving meaning from these personal and social experiences at diagnosis can reveal the psychological processes that mothers of children with a disability undergo, given their unique circumstances. Whether the diagnosis of a disability is given at birth or at a later life stage, the emotional trauma, mental anguish, and feelings of loss and isolation that mothers endure cannot be understated (Boström, Broberg & Hwang, 2009; Singh & Chopra, 2020). In a study done by Barbosa, Chaud & Gomes (2008) the researchers sought to uncover the meaning of the experiences of mothers of disabled children. They found that the entire family had to start “an adaptation battle to recover their balance” (p. 47) after hearing the diagnosis of their child. These authors identified that the knowledge of a child’s disability is a traumatic one and can severely affect the emotional state of all members of the family. The mother can experience disappointment, inferiority, rage, and grief for “the loss of the desired child” (p. 48). These kinds of first-hand experiences at the diagnosis stage can stem from the medicalized notion of disability (Landsman, 2009). As diagnosis is given by medical experts, mothers may tend to believe them and think that there is no cure for their children’s “illness” which they may confuse with a disability. Other researchers (Green, 2005; Goffman, 1963; Yousafzai, Farrukh, & Khan, 2011) believe that such emotions can have a devastating effect on the psychological wellbeing and emotional state of a mother.

2.3.2 *The Psychological Well Being of Mothers*

Sometimes mothers may tend to think that having a disabled child is a tragic occurrence and they live in sorrow as they watch their children grow (Goodley & Tregaskis, 2006; Oliver, 2013). Oliver (1990) postulates that impairment is usually assumed to be a personal or familial tragedy. Goodley & Tregaskis (2006) argue that “breaking the news” of disability to parents is an area of concern because it promotes the “pathological and tragic view of the child” (p. 637) that stems from the negative values society has about children with a disability. These authors also contend that parents, particularly mothers, have to go through several hurtful processes of acceptance and denial which are complex in their nature. From other research conducted, mothers

expressed that others in society need to see the value of the lives of both their child's, as "a life worth living" (Landsman, 1998; Goodley & Trekgaskis, 2006; Lalvani, 2011) and their own life as mothers and caretakers. In this regard, Harvey and Long (2020) suggest that a mother's psychological wellbeing can temporarily collapse when she has a child with a disability. Hence, as a researcher on the topic of disability, I feel it is imperative to know and to understand mothers' experiences in order to promote their enablement so that they can deliver care and support for their children.

Zulfia and Allenidekania (2020) in conducting research on caregiving experiences hold the view that the most intense experiences occur after diagnosis, where mothers may encounter feelings of loneliness, physical and mental health problems, social isolation, and impediments in carrying out the caregiving role. These authors argued that mothers' problems are intrinsically associated with their personal feelings and hindrances in fulfilling the role of a caregiver (Zulfia & Allenidekania, 2020). Some mothers whose first encounter with a disability is with their children's diagnosis may feel that disability diminishes their "personhood", their personality, or even their motherhood (Gabel, 2018; Landsman, 2005; Lalvani, 2011). These feelings can arise firstly, because they may never have imagined having a child with a disability or, secondly, because of the preconceived notions they hold about disability. These assumptions or constructions can have their roots in the way society has been traditionally conditioned to think of disability, that is from a pathological perspective (Oliver, 2013). For mothers, this may mean that in going forward, they must adjust their mindset (Carlson & Miller, 2017) and prepare for what lies ahead of them and how their role as mothers may change in caring for the children who have a disability.

A recent study by Harvey and Long (2020) explored the stories of two mothers and the complicated ways these mothers of physically disabled children treat with abjection in their interactions with their children. Abject, as these authors state, can come from the unique relationship mothers have with disability, describing it as "so close and yet so far" (p. 462). They were referring here to the fact that non-disabled mothers having disabled children where they experience a love-hate relationship (the abject) which causes feelings of ambivalence (Harvey & Long, 2020). According to these writers, such experiences include "*unsharable*" (p. 460) or unthinkable thoughts that cannot be divulged to any "normal" person but ones they (the mothers who were studied) shared

with the authors. According to Harvey and Long (2020), this emotional state of ambivalence or uncertainty may cause mothers at times to have deep hate feeling for their disabled children. Such conflicting emotions relate to the perceptions or battles of self that the mother experiences in caring for her visibly physically disabled child. These authors also note that it is essential to understand the multifaceted aspects of mothers' caregiving experiences including those that are "shocking or linked to horror" (p. 462), which they say people may not want to admit happens. However, the biopsychosocial model of disability, proposed by the WHO (2011), addresses this area of concern which focuses on supporting disabled persons (or caregivers of children in this case). The WHO (2011) notes that personal factors can be taken into account when assisting parents to manage their psychological wellbeing. An understanding of maternal experiences can promise insight into ways one can help mothers care for their disabled children or embrace disability in a deeper and more positive way.

The uniqueness of mothers' experiences in caregiving entails not only negative feelings but also positive ones that are not sufficiently represented in the literature (Bourke Taylor, 2010; Green 2007; Lee 2013; Zulfia & Allenidekania, 2020). This lack of inclusion on the positive aspects of disability can inadvertently encourage a pessimistic or chronic view of disability and caring for children who have a disability. Apart from the stresses and burden of care, Ferguson (2002) contends that one's interpretation of disability reflects the social attitudes and historical realities of the society in which one finds themselves. He further suggests that our interpretation of families experiencing disability is deep-rooted in the "hidden assumptions and cultural expectations of a specific era" (Ferguson, 2002, p. 124). Therefore, one must be cognizant of the fact that one's understanding is tainted with one's cultural perceptions whether they are positive or negative, and which can impact the treatment of mothers who care for their disabled children. The understanding of how mothers derive meaning from their experiences and the way these experiences can translate into joy and happiness from parenting disabled children is worth considering if one considers the "humanness" of their experiences (Kim & Hwang, 2018).

Trute, Benzies, and Worthington, (2011) maintained that sometimes parents experience both happiness and sadness to the same life challenges. While there are very challenging circumstances surrounding raising a child with a disability, research has

found that mothers also experience significant “blessings” over time (Bourke-Taylor, 2010). With social support or positive perceptions, mothers can become optimistic and respond to situations with strength and fortitude, otherwise known as resilience (Halstead, Griffith, & Hastings, 2017; Heiman, 2002). It is possible also for mothers to become more courageous and emotionally stronger in overcoming the discrimination or exclusion and the plethora of barriers they face in society. The old adage, “patience is a virtue” is a lifetime practice for mothers who parent a child with a disability. According to Halstead, Griffith & Hastings (2017), having a child with a disability practically made some mothers feel that they have more structure to their lives, more patience, and endurance. For example, a mother caring for a child with cerebral palsy or delayed development cannot rush the child because he/she will not function in the same way as a non-disabled child. Therefore, mothers learn to or are even compelled to exercise patience and tolerance in attending to their children’s special needs, regardless of the mental or physical strain it may take from them.

2.3.3 *Maternal Love*

Amidst the cornucopia of negatives, problems, and disenchantment of having a child with a disability, mothers also experience positive emotions. How do they do this? One such explanation can be the act of maternal love. In an extensive study entitled “The Neuroscience of Maternal Love” conducted by Kikuchi and Noriuchi (2015) and which hinges on attachment theory, they found that maternal love accounts for the motivational factors responsible for the behaviour of a mother in her caregiving capacity. These authors underscore that it is this love that induces a mother to make the level of sacrifices needed in caring for her child. As they put it, “this love is a dynamic force that empowers a mother to remain vigilant and sustain the exhausting schedule involved in protecting and nurturing an infant” (p. 2). Although maternal love can be applied to all mothers, the mothers who raise children with a disability exhibit more resilience than those who do not. This maternal love, according to Kikuchi and Noriuchi (2015) has an impact on the infant’s resilience (Savari, Naseri & Savari, 2021; Choi & Yoo, 2015), which is in itself, not only a positive but an admirable quality.

Other research shows that mothers also learn love from their children who reciprocate this love to them unconditionally. As their children grow, mothers of disabled children learn to believe in their children and not accept that they are difficult and cannot

progress (Roopnarine, Logie, Davidson, Krishnakumar & Narine, 2015). In other words, mothers' positive perceptions came about because of the positive contributions their children have made to their own lives (Halstead, Griffith & Hastings, 2017).

In this section, I addressed research question one, which seeks to explore the lived experiences of mothers who care for disabled children. I choose to look at the value and relevance of those experiences questioning why it is important to know of their experiences. The literature has shown that mothers of disabled children experience a higher degree of stress which impacts their psychological and physical wellbeing. However, the distinctiveness of their experiences also reveals that despite these negative feelings they still experience positive emotions, which stem from the strong maternal bond that is inherently present in most mothers. Such insights can provide learnings to the government and the wider public to rethink how they view mothers who parent children with a disability. Such learnings can be beneficial in crafting policies and laws to benefit all persons living with a disability.

2.4 Mothers' Perception of their Caregiving Role

Qiong (2017) notes that in philosophy, and psychology, perception is defined as "the process of attaining awareness or understanding of sensory information." (p. 18). The author notes that perception follows three processes, namely *selection*, where a stimulus from the environment is altered to have meaning; *organization*, which is finding meaningful pattern; and *interpretation* which is the process of attaching meaning to the stimuli (p. 18). Qiong went on to say that these three processes act in tandem to create a *perception*. Since perceptions are based on the interpretation of selected and organized stimuli, meanings are created. These meanings over time become durable. Hence the partiality of perceptions is what causes misconceptions especially if people hold different beliefs of the same concept, such as disability, their experiences and interactions will vary in terms of culture and background (Qiong, 2017).

In relation to this review, I found it was important to understand the notion of perception as it will inform the discussion on why and how mothers perceive their caregiving roles and that of others. There is a lacuna of literature on the way mothers perceive their roles in caring for disabled children. Harvey and Long (2018) and Harvey (2019) establish that mothers' subjective experiences are indeed an area that needs more

exploration. This research will look at one aspect of mothers' personal and social experiences by exploring mothers' perceptions of their role in caring for their disabled children. This section addresses research question two of this study.

Historically, disability research concentrated on the charitable and medical models of disability (Oliver, 2013; Cole, 2007; Ryan, 2005). This medicalized paradigm takes a pathological view of disability and locates the problem within the individual (Retief & Letsosa, 2020). This view of disability aligns itself to the belief that disabled children or all disabled persons are "defective" or almost less than human (Goodley, Lawthom & Runswick, 2014). Such an assumption about disability can leave mothers feeling that their children will always be incomplete, a misfit (Garland-Thompson, 2011), or an "outsider" (Ryan, 2005, p. 292). An understanding of this prevailing thinking situates disability in the minds of mothers as something unfortunate probably long before they even conceive children (Kuhn & Carter, 2006; Goffman, 1963). Such feelings or thinking can have a profound impact on the psychological well-being of mothers and cause them to react in different ways. As a result, they assume different roles as distinct from typical mothers parenting typical children.

In exploring how mothers perceive their caregiving or nurturing roles, one may wish to ask the question as to why do mothers have those perceptions or beliefs about disability in their minds. There are several factors that I will explore to address this more provocative question in a bid to understand why they assume the roles that they do. These factors include the notion of ownership, cause, responsibility, and competence. Additionally, the ensuing discussion will show how stigma, blame, and guilt also has a way of influencing mothers' perceptions of their roles.

2.4.1 Ownership

There is a dearth in the current literature that addresses the notion of ownership which refers to the responsibility held by mothers in caring for children with a disability. I found only one journal article by Diane Jeske (1996) that reviewed this subject specifically, which might be indicative of an opportunity for further research in this area. As this research is set in Trinidad and Tobago, mention must be made that there is no literature on the subject of mother-child care ownership in Trinidad and Tobago. However, I found the topic of ownership to be an interesting concept in determining what

accounts for the perceptions of mothers' in their caregiving roles. From a personal perspective, a mother's deep need to protect her child with a disability can come from the thought that as she is the one who "created" this human being, and the child is her sole responsibility and therefore her property (Jeske, 1996). From a social constructionist view, the way mothers are perceived by others in society as primary caregivers, and the way they come to internalize this concept of their role, put them in a position to think of their children as ultimately their own, whether or not a father or others are present. In other words, it may be a question of authority that mothers feel they may have, that is the right over their children. Additionally, the legal systems in most countries, including Trinidad and Tobago award mothers the first preference (under normal circumstances) for custody of their children. Hence this may carry the assumption that it is the mothers who have prime responsibility for their children.

The theory of liberty founded by John Locke in the early eighteenth century is a political theory of liberalism that alludes to owning property rights. The theory suggests that each person is a "self-owner" (Jeske, 1996, p. 137). Jeske argued the point that since each of us is a self-owner, then women "have property rights in the products of their labor, including their infants" (p.143). Jeske cited Okin (1989) as saying that it is only women who have the capacity to engage in that kind of labour to produce other human beings. They are the ones who carry their children to term and nurture them during and after pregnancy (Jeske, 1996).

The notion of owning property, however, must be understood in today's terms of human rights. This means that mothers can 'own' their children up to a certain point in a child's life, that is until children can exercise their rights independently. However, for the sake of this argument, I am projecting the thought that some children with a disability may never reach that point where they can truly exercise their own rights. As a result, their mothers or caregivers will exercise or "own" that right to protect them. However, I must mention here when I speak of ownership, it is not for mothers to dehumanize their children and take their minds away from them or objectify them in any way. My argument is born out of the need to understand *why* they assume such intense caregiving roles (Woodgate et al., 2015) and why they may feel the need to be lifelong protectors of their disabled children. This is one way by which mothers become agents, advocates, and activists for their children's rights (Boshoff et al., 2016). If we consider mothers'

perception of their role as ultimately protecting their children with a disability, then we can understand the extent they will go and the extent of their sacrifices in protecting what is theirs. In relation to the lack of support from others, government or family (Crettenden, Lam & Denson, 2018), for instance, mothers may interpret their ownership roles to mean something like this: “*This is my child and I will do anything I can to take care of him/her regardless of what anyone else may think or say*” (my words). Words to this extent can be internalized thoughts that a mother may have in assuming the intensity of her parenting roles.

2.4.2 *Mothers’ Perception of the Cause of Disability*

This notion of ownership therefore can be linked to mothers’ perception of themselves as being the cause of their children’s disability. The cause to which I refer is distinct from blame which can come from the public’s perception influenced by traditional stigmatized beliefs held by the mother or by society. Being the only individuals responsible for their children growing inside of them, mothers of children with a disability may conceptualize their children’s disability as resulting from something bad or wrong that they have done (Landsman, 2005; Gupta, 2011; Munyi, 2012). Hence mothers may see themselves as being the cause of their children’s disabilities.

In one way, strong feelings of blame and guilt will emerge that can influence the way mothers may think of their caregiving role/s. In another vein, to draw an example, if a mother is beaten by her husband or raped before giving birth, and the child incurs a disability, she may have feelings of “ambivalence” (Harvey, 2018; Harvey & Long, 2018), thinking it was not *her fault* that child has a disability. This can result in her nurturing bitterness and hatred toward the child knowing at the same time the child is hers and hers alone. These feelings are what Harvey and Long refer to as the “abject” (Harvey & Long, 2018, p.460-479). Therefore, relating to the experiences mothers encounter before birth or after diagnosis, whether they be positive or negative, will have the potential to cause them to see their obligation to their children as solely their responsibility.

Mothers feeling of guilt, sorrow and self-blame can result from thinking or watching their children “suffer” through their disability (Brown, 2013; Tsai, Tsai & Shyu, 2008). Such sentiments may also emanate from experiences relating to mothers’ pre-natal

care during pregnancy (Landsman, 2005) such as an unhealthy diet, being over-worked, stressed, or taking drugs or alcohol. Mothers may also feel guilty and blame themselves for having defective genes (Nazzal & AL-Rawajfah, 2018). Blame and guilt can also be manifested by high levels of stress because of unmet expectations, both from the mothers themselves or from others (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016). Hence self-blame and guilt can be projected onto the roles and the intensity of mothers' capacity to optimally care for their children with a disability.

In many instances, guilt comes from relations mothers have with others, such as family or relatives (Boshoff et al., 2016) or even medical professionals (Collins & Coughlan, 2016). In other words, the construction of thoughts regarding blame and guilt can be as a result of perceptions mothers hold about society's perceptions of disability as well as perceptions and expectations of their roles as mothers of children with a disability. Such perception can be formed from cultural and traditional thinking (Qiong, 2017). For example, religion may be a factor that would lead mothers to blame themselves (Retief & Letšosa, 2018). Depending on their religious beliefs, mothers may assume that having children with a disability is a punishment or its God's Will that such a *tragedy* has befallen them (Kamenopoulou & Dukpa, 2018; Lalvani, 2011) alluding to the religious or moral model of disability. These types of traditional perceptions held by the larger society also condition how the mother may think of disability before she even brings a disabled child into this world. This scenario alludes to the social model of disability and the social constructivist theory of reality discussed previously, where the construction of reality (in this case, those of the mothers) about disability is relative to experiences, upbringing, or culture. Support from family and others in society has understandably been identified as a positive factor that will cause mothers to have a more positive attitude towards disability (Boshoff et al., 2016; Ryan & Runswick-Cole 2008) rather than blame, guilt, and sorrow that comes with the stigma that underlies them.

2.4.3 *Stigma*

Stigma to a great extent determines and underlies the perceptions and beliefs mothers may have about disability. Cantwell, Muldoon, and Gallagher (2015) cited Goffman (2009) on defining stigma as the impact of "negative attitudes and behaviours" from the public which usually results in "negative psychological and physical health for the stigmatised individual" (p. 948). Goffman (1963) also puts forward that a stigma is

an attribute of a person that is “reduced in our minds from a whole and usual person to a tainted, discounted one,” an attribute that is considered “deeply discrediting” (p. 3). These attributes, he observes, reside in the interactions between the individual who possesses them and others in society who see them in a negative way or as “objects of devaluation” (Gona, Newton, Hartley & Bunning, 2018, p. 2). Such perceptions align to the social construct of disability, where people are said to construct personal truths given their unique experiences (Anastasiou & Kauffman, 2011). Therefore, disability is a stigmatized social identity that influences the structure of intersubjective relations in different ways. A mother therefore living in a society that distorts the attributes of her child because of a disability, will have trouble in relationships with others as she may perceive their biases as a projection onto her child as well as herself (Harvey, 2018).

Echoing Landman’s (2003) idea, Carpenter and Austin (2007) state that mothers “experience their child’s label as their own disability” (p. 662), and that disability diminishes personhood through discrimination and segregation. In other words, mothers also experience this stigma by introjection (Harvey, 2018), meaning that they absorb the social construction of disability from the society in which they live. Green (2003) also cited Goffman (1963), as saying that stigma not only affects the experiences of disabled persons who are stigmatized but that it also spread to the others who associate with them. Thus, Goffman purports that close friends and families of disabled children can acquire a *courtesy* stigma because of their relationships with those who are stigmatized (Goffman, 1963; Green, 2003).

Green (2003) also agrees with Goffman, recognizing that stigma is a complex phenomenon that affects people “within the same community of others” (p.1362); for example, members of the same family can experience different degrees of stigmatization. Reacting to this stigmatization, mothers may withdraw or try to hide their disabled child since they may perceive their negative status from others (Goodley & Tregakis, 2006). A ripple effect may be that such an action can potentially negatively affect the “social support, self-esteem and psychological health” (Cantwell et al., 2015, p. 949) of mothers (Scotch, 2000). In other words, stigma can cause a lack of support from others which will impact the psychological wellbeing of mothers (Singh & Chopra, 2020) and which can negatively affect their capacity to effectively care for their children. According to Tekola, Kinfu, Girma, Hanlon and Hoekstra (2020), the reverse which is the support of

family, government and community will, therefore, increase mothers' mental wellbeing causing them to be stronger in their caregiving burdens to support their disabled child.

2.4.4 *Maternal Competence – “Experts by Experience”*

Living among non-disabled people or “normals” as Goffman, (1963, p. 5) calls them, referring to persons who stigmatize the disabled population, can affect mothers' perception of disability to the extent that their role as the main caregiver expands to encompass a variety of other roles (Collins & Coughlan, 2016) such as educator, protector and advocate. In a study conducted on mothers who parent children with Down Syndrome, Isgro (2015) posits that sometimes mothers and caregivers in general are tossed into the “uneasy” roles of “advocate, policy-maker, and teacher” (p. 63). In other words, mothers are the agents and ambassadors for their children's every major need (Cole, 2007; Khun & Carter, 2006). As individuals who assume these roles described as intense parenting (Woodgate, Edwards, Ripat, Borton & Rempel, 2015), mothers can perceive that no one else is as competent as them in delivering care to their disabled children.

This concept of intense parenting to which mothers may subscribe, is described as “labour intensive requiring a readiness to provide care at any time” (Woodgate et al., 2015). Consequently, mothers may see themselves as mini experts in their role as caregivers (Gona et al., 2018). This notion of being the care expert can influence mothers' judgment and make them question the capability of others to care for their children who are disabled. Their unrelenting exertion for their children can lead others to pity mothers for their extensive caregiving roles (Dehghan, Dalvandi, Rassafiani, Hosseini, Dalvand, & Baptiste, 2015), resulting in additional mental stress. Becoming “experts by experience,” a term used by Gona et al. (2018), suggests that mothers assume different roles and master them, making mothers themselves the only ones who thoroughly understand and accept their children as they are. Such self-training comes at a heavy cost burden in terms of time, energy, money, and psychological stress (Gona et al., 2018). Consequently, mothers may think they know better than anyone else, what is required to manage their children. Since mothers *know* of the degree of sacrifice required to care for disabled children, their ability to trust others to do the same will be fragile.

Protector Role

Mothers are painfully aware of why they must be the protector of their children. Disabled children are assumed to be a vulnerable population and need protection (Groce, Kett, Lang & Trani, 2011; Goff, 2016; Jahng, 2020; Shah, Tsitsou & Woodin, 2016; United Nations, 2018). Goff (2016), in a study done in Scotland, notes that disabled children are “3.4 times more likely to be abused than non-disabled children” (p. 74) by others in society because of their susceptibility as well as the inability to care for themselves. He suggests that practice, referring to teaching, should be focused “more on the parent/carer than the child” (p.74) as harm can more likely befall these children. The vulnerability of their children and the negative attitudes of people, such as pity, curious stares (Dehghan, et al., 2015), or ignoring the disability has the propensity to make mothers sacrifice much of their time to ensure the protection of their children.

Nazzal & AL-Rawajfah (2018) posit that mothers’ overwhelming need to protect their disabled children can emanate from feelings of fear of the future and of death, their death. These authors also pointed out from their study on mothers’ lived experiences that the mothers painfully admitted that they hoped their children’s death come before their own, because of the extent of the worry they feel for their children’s future survival. Such morbid feelings can place an extreme amount of psychological pressure on mothers. As a mother myself, the thought of my children dying before me is almost inconceivable.

The degree to which mothers extend themselves in their caregiving role can also stem from the severity of a child’s disability. Mothers may fear greater if their children are profoundly disabled, or if they have comorbid conditions of illness and disability, thinking that there will be no one as capable as them or even *want* to lend support to care for such a child (Halstead, Griffith & Hastings, 2018). Therefore, mothers’ perception that their children can suffer after their own death impacts upon the degree of sacrifice they will make to protect their children’s survival. For those children who have some degree of functionality, mothers may seek to equip their children with certain skills such as academic and survival skills as well as they may seek to ensure financial protection so that if they die their children will be able to live.

Educator Role

Junaidi and Dewantoro (2020) suggest that “parents’ perceptions of children who have a disability determine how parents educate and care for the child” (p. 14). Therefore, if parents feel that education is a key to survival for their children, then they will assume greater effort in securing an education for their disabled children. Mothers may have certain conceptions about education itself, such as it being a way to cope better in a stigmatised society whilst living with a disability. Mothers can also assume that formal schools, being a main socializing agent for their children (Quamina-Aiyejina, 2000) can mean a greater degree of acceptance and inclusion into society (Junaidi, & Dewantoro, 2020). Therefore, with reference to mothers’ perception of how she views her role as both a protector and an educator, mothers may assume the role of “mother-teacher” (Cole, 2012) opting to home school their children if the education system does not provide sufficiently for their disabled children.

Advocate Role

Persons with disabilities including children, living in a stigmatized environment can lose their voice causing further disablement which can incite mothers to be the voice for their children (Koch, 2020). Landsman (1998) notes that advocacy for disabled children becomes part of a mother’s identity born out of the “child’s humanity and of the fear that one’s full value of the child is missed by others” (p. 87). This devaluation and dehumanization can be alluded to what the social model of disability refers to as oppression (Oliver, 1990). Striving for their children to be fully accepted as full human beings (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016; Van Trigt, Kool & Schippers, 2016) stretches a mother’s caregiving role to the point where she gives up part of her life and sacrifices everything possible for the wellbeing, the rights and happiness of her child (Mokhtari, & Abootorabi (2019). Advocacy is also aligned to the principle of fair and equal treatment for disabled children, aligning itself to the human rights model of disability (Degener, 2016) as well as the dignity of disabled children. The dedication and extension of voice are what differentiates mothers who parent disabled children from those who do not, and such consideration would probably not be conceivable without the social model of disability. Hence advocacy or speaking on behalf of and for their children can be seen as a necessary action by mothers who parent disabled children.

2.4.5 *Maternal Self-Efficacy*

Mothers' self-efficacy is an important factor in their perception of being able to fulfill their roles as the main caregivers for their disabled children. Kuhn and Carter (2006) defined parental self-efficacy as "feelings of competency in the parental role, termed parenting self-efficacy, have been associated with well-being and positive parenting outcomes" (p.565). According to Kuhn and Carter, self-efficacy can be described as the way a mother may judge how well she functions in her caregiving capacity with respect to the challenges she faces in her complicated caregiving roles. Research has shown that the psychological legacy of being blamed for their children's disabilities can contribute to the social stigma they may experience (Koch, 2020). From a psychological perspective, this stigmatization will most likely result in mothers carrying feelings of blame and guilt which can negatively affect their feeling of competency in caring for their disabled children.

Based on the teaching from Bandura, researchers (Al-Kandari & Al-Qashan 2010; Kuhn & Carter, 2006) point out that self-efficacy can be influenced by other variables such as the perceived difficulty of caregiving or the extent to which mothers understand and can control the behaviours of their children. This is why a support mechanism is needed for mothers who parent disabled children. Mothers may more likely persist in their caregiving roles if they have support from family or from the wider society. Given the uniqueness of the experiences of these mothers, this support will have a positive effect on her mental wellbeing. Without social support, mothers may perceive their tasks as more burdensome and feel more stressed (Al-Kandari & Al-Qashan, 2010). Conversely, feelings of competency can be more positive if they feel they are more likely to succeed in their caregiving roles. Situations where mothers feel they have limited control (Al-Kandari & Al-Qashan, 2010) such as inadequate access to educational and social services and societal stigmatization can, therefore, affect mothers' perceptions of their competency in parenting their disabled children.

This section of the review addressed research question two which examined the nature in which mothers perceive their caretaking roles. The discussion encompassed the concepts of ownership, responsibility, competence, stigma, blame, guilt, and maternal self-efficacy. An enhanced understanding of how and why these factors affect mothers'

perceptions of their role as a caregiver of disabled children can invite others to render the much-needed assistance for these mothers.

2.5 Mothers' Perception of Government's Role

In this section of the review, I address research question three of this thesis. In the previous section, I highlighted the ways in which mothers perceive their caregiving roles. Here I will explore mothers' perceptions of the government's role in providing formal education, social services, legislation, and socialization opportunities for disabled children. An understanding of mothers' views can have implications for, firstly, the way equal opportunities for disabled children are addressed, and secondly, the way legislation is crafted to address the issues of inclusion and support for disabled children and their caregivers. While this literature review draws mostly on research from international studies, this section of the research will have a greater focus on Trinidad and Tobago.

Literature can be found from international organizations on the overall role or responsibilities of governments in providing educational and social support services for the disabled population. These international bodies also provide policy guidelines for education and disability, through conventions held by the Economic Commission for Latin America and the Caribbean (UNESCO, 2009), the Convention on the Rights Of Persons With Disabilities (CRPD, 2008), the Convention on The Rights Of The Child (UNICEF, 2008), the World Report on Disability (WHO, 2011), the Salamanca Statement (UNESCO, 1994); the Dakar Framework For Action, Education for All (EFA, 2000), and the Situational Analysis of Children in Trinidad and Tobago (UNICEF, 2017). Specific to Trinidad and Tobago, there is some research available on inclusion given from an educational or economic perspective (Conrad, 2006; Lavia, 2007; Charran, 2018; Johnstone, 2010; Seetahal & Charran, 2018; Quamina-Aiyejina, 2003).

However, addressing the perceptions of mothers in Trinidad and Tobago does not seem to be a top priority for consideration in research as seen in the dearth of literature on this topic. Consequently, I will concentrate on the role of government, focusing on the context of Trinidad and Tobago, in providing formal education because the absence of the same can imply that mothers parenting disabled children will have to find some recourse to educating their children. This may include home-schooling, which could place

an additional burden on mothers' caregiving roles or paid school, which may involve additional expenses.

2.5.1 Government's Role in Educating Children with Disabilities

Education is an important aspect of development for disabled children and their caregivers. If the formal education systems fail to optimally provide for disabled children, the burden befalls the parents or caregivers. According to the WHO's 2011 World Report on Disability, the research found that generally, in developing countries such as Trinidad and Tobago, disabled people experience "lower employment rates and lower educational attainment" (p. 39) as compared to non-disabled persons. In 2005, the United Nations Children's Fund (UNICEF) averaged that there were 150 million disabled persons worldwide under the age of 18 (WHO, 2011). Based on the most recent 2011 census report in Trinidad and Tobago, there were 3,302 children living with a disability, representing one percent of the child population and 6.3 percent of all people with disabilities in Trinidad and Tobago (CSO, 2011; UNICEF, 2017), which is relatively high given the population size. There are twelve public special schools in Trinidad and Tobago (UNICEF, 2017). A hypothetical, rough calculation of placement of disabled children into these public schools reveals approximately 275 children in each school assuming that there is no option for private education. For children with a disability, the ratio may need to be lower, considering that there are different types of impairment, with varying levels of intensity. Research shows that the average child-staff ratios range from 5 to 14.5 preschool-aged children per teacher with a mean of 8.65 (Perlman, Fletcher, Falenchuk, Brunsek, McMullen & Shah, 2017, p. 1). However, applying this ratio to Trinidad and Tobago, there would need to be at least thirty-one teachers in any given special school, which government schools may not have the resources to accommodate. In such a scenario, disabled children risk being left behind, making the care burden of mothers even more pronounced.

If lower-income parents cannot afford private schooling and if the government schools are overpopulated or understaffed, then some children will have to remain at home or not attend any formal educational institution. Parey (2020), in a study on the wellbeing among working-age persons living with a disability done in Trinidad and Tobago, found that 23 percent of the participants received no formal education. In such instances, the responsibility of education and care falls on the shoulders of parents and,

in most cases, mothers, as they are the primary caregiver (Lalvani, 2011). Already heavily burdened mothers (Ghazawy, Mohammed, Mahfouz & Abdelrehim, 2020) having to take on the extra and seemingly unfair responsibility (since the system allows them no other choice compared to mothers of non-disabled children) of home-schooling their disabled children can be concerning given the potential for the negative impact on mothers' health and wellbeing as well as on the optimal development of their children (Ghazawy et al., 2020).

Additionally, as education of persons with a disability requires specialized training, mothers may not be equipped with the skills to "teach" their children following the same level of expertise offered at a formal school setting (Owusu, Enoch, Mprah & Vampere, 2018). Mothers may feel hopeless when schools are unable or unwilling to accept their children (Munyi, 2012). They may feel that their children are denied the right to a formal education compared to non-disabled children because of their obvious differences. This perception of being unfairly treated mothers can be justified based on the constitution of Trinidad and Tobago which articulates that education is compulsory for all children from the age of six (UNICEF, 2017; Williams, 2007; Parey, 2020). Their perceptions may also be justified from a human rights perspective, which identifies that all persons with a disability have the right to work and obtain education (Degener, 2014). In another study done in Africa by Owusu et al. (2018) on parents' perceptions of education, the researchers found that depending on the severity of the disability, parents were very pessimistic of sending their disabled children to formal schools. They considered that their children were uneducable. However, most parents remain optimistic about the benefits of formal schooling, provided that it is made accessible to their disabled children (Owusu et al., 2018).

Mothers of children with a disability may experience significant disillusionment when their children are not accepted into a formal institution which can result in the loss of confidence in the government and its education system. The United Nations and all of its associated international bodies explicate that education is a basic human right of the child. Considering this, as Trinidad and Tobago is a signatory to many international conventions, the country, therefore, has a commitment to ensure that the rights of disabled people are upheld. While there have been efforts by the Trinidad and Tobago government towards inclusive education (Conrad et al., 2010; Lavia, 2007; Parey, 2020) inclusion of

all disabled children seem like an elusive goal. Lalvani (2011) notes that mothers' unique experiences in parenting a child usually involve "*fighting*" for the rights of their child (p. 285). Hence, mothers' perceptions may be that more can be done in addressing the educational needs of children, given the fact that the government is the only institution that can control formal education to include children with a disability in the mainstream public school system.

2.5.2 *Socialization*

Socialization is a benefit of formal education of which is a direct responsibility of the government. Zvoleyko, Tatiana, and Klimenko (2016) identified socialization as "the process and the result of the inclusion of an individual in social relations" (p. 6471). For disabled children, socialization is an important aspect of development. It is often seen as an avenue for participation for such children into society, access to knowledge, education, and cultural values (Zvoleyko, et al., 2016; Owusu, et al., 2018), and which additionally affords children a sense of identity and belonging. Mothers trying to home school their children in the absence of a formal school environment cannot provide this means of integrating into society. Additionally, Cemalcilar (2010) notes that a formal school environment provides "the context in which the first significant relationships with people outside the family are formed" (p. 248) Therefore, children have the opportunity to interact with teachers, administrators, peers, and other adults which is healthy for the growth and development for disabled children (Cemalcilar, 2010). Schooling gives children a chance to form an identity, have relationships outside the home and learn different behaviours, which are important developmental milestones for young disabled children. As Zvoleyko et al., (2016) mentioned, disabled children "are often hyper-protected; thus, their social development is blocked and development of personal autonomy and freedom of decision-making are not ensured" (p. 6477). Such conditions can result from the well-meaning and intimate care that comes from mothers in the home environment. Therefore, there is value in the process of socialization in a formal setting as it relates to the educational development of disabled children.

Schools for disabled children provide a means for establishing social relationships as well as interacting with the built environment (Jackson, 2018). Whereas at home, children will interact with the same family members in the same space which is the home environment, formal schools provide an opportunity for interaction with a structure such

as classrooms, equipment, playgrounds, and teaching-learning materials (Cemalcilar, 2010). When mothers can send their children to public schools, they may be more inclined to feel a degree of safety and peace of mind knowing that their children are having the necessary positive social development. Formal schooling also presents a degree of integration for disabled children into the larger society (Zvoleyko, et al., 2016). Owusu, et al. (2018) found that there are growing positive perceptions from adults on educating disabled children which accounts for the increase in knowledge about “national and international legislation and policy frameworks” (p. 682). In most countries, as in Trinidad and Tobago, public education is funded by the government. Hence when children cannot enter into the public educational system mothers may adversely think that government does not care or that it is not fulfilling its role in serving the more vulnerable children in society.

2.5.3 Education and Employment for Children with Disabilities

Mothers’ concern for education is also linked to the employment of their disabled children when they reach an age of employability. A general feature of education is that it strongly correlates to employment. The World Education Forum in 2000, adopted the “Dakar Framework for Action, Education for All (EFA): Meeting our Collective Commitments” which stresses that all children should be educated and calls upon governments to ensure that this happens (UNESCO, 2000). Both the Education for All (EFA) goals and the Convention on the Rights of Persons with Disabilities (CRPD) places education as a top priority as it is linked to increasing literacy, knowledge, and employment opportunities for disabled persons (Parey, 2020; UNESCO, 2018) Seetahal and Charran (2018) concurring with the WHO (2011) identified that globally, the employment rate of people with disabilities in 2011 was 44%, compared to 75% for people without disabilities. Baker, Linden, La Force, Rutledge, and Goughnou (2018) also found that apart from the large percentage of disabled persons who are globally unemployed, it was the attitude of employers towards disabled persons that pose a barrier toward employment. The perception that that disabled persons are under-educated and unproductive is a misleading conclusion by employers (Baker et al., 2018) and reverberates the Economic Model of disability which further underscores the need to lower stigmatization of disabled persons.

Generally, mothers or families will not be able to provide employment for their disabled children and may depend on the state or private entities to do so. Being employed and earning a living encourages independent living and is linked to greater integration into the general public sphere (Seetahal and Charran, 2018; WHO, 2011). Paid employment will further help reduce the welfare view that society holds about disabled persons and the dependency on charitable organizations, thereby reducing the stigma of disabled persons (Goffman, 1963; Reitief & Letsosa, 2018; Oliver, 1990). Additionally, mothers may see the link of formal education to employment as a means of progress for their disabled children (Lalvani, 201; Conrad et al., 2010). Like other parents, they may want their children to have a semblance of “normal” living as they grow older and into adulthood and may view employment as a means to accomplish this goal. From an equity perspective, mothers may perceive the government as having both the capability and capacity to effect changes that will encourage employment for disabled children because they have the budgetary allocation and other resources to do so. This may not be an unjustified view as Trinidad and Tobago has been noted as one of the wealthiest countries in the Caribbean with a well-educated population (Persons, 2018; UNICEF, 2017). Hence mothers as the main caregiver of disabled children may perceive the government as being both capable and responsible for the education and employment of disabled children but are inefficient in ensuring equal access and opportunities for the disabled population.

2.5.4 Legislation

More about the value of legislation for disabled persons is needed in the research agenda in Trinidad and Tobago. Apart from being responsible for formal education, governments, specifically in Trinidad and Tobago also have a responsibility to uphold the international mandates such as the Convention on the Rights of the Child, Education for All goals, and the Convention on the Rights of Persons with Disabilities (CRPD) to which it signed (Seetahal and Charran, 2018). One way by which the Trinidad and Tobago government can fulfill this obligation is through legislation. The only piece of legislation in the country that act as a protection for disabled persons is the Equal Opportunities Act (EOA) of 2000 (National Policy on Persons with Disabilities, 2018), which states that whatever is the “status” (which includes those with disabilities, and which I think is a vague term) of a person, they should be free from discrimination (Seetahal & Charran, 2018, p.134). As I have established earlier, there is limited literature in Trinidad and Tobago on disability, including the area of legislation.

The importance of legislation for disabled children cannot be understated since it may attempt to lessen the historical stigma that pervades society (Charran, 2018; Seetahal & Charran). As laws offer a degree of protection for people, mothers may see this action as positive by the government by securing a reasonable amount of fair and equal treatment for their children. While there is a deficit in legislation for disabled persons in Trinidad and Tobago, policies do exist. UNICEF (2017) states that there were a number of pieces of legislation that were proclaimed in mid-2017 (p.12) relating to children. However, the proclamation does not mean that it is the law. Additionally, there is a national policy for disabled persons that was established in 2018 (National Policy on Person with Disabilities, 2018). This policy identified the need for increased research on disability in Trinidad and Tobago as well as the need for further legislation to bring the country in line with its international mandates (Charran, 2018). The policy aims are to uphold the articles in the CRPD namely the human and equity rights for disabled persons. While the policy indicates that legislation was at the top of the Trinidad and Tobago government's agenda in 2018, three years after, there is still no new or noteworthy movement to its implementation. Hence mothers who parent disabled children may conclude that not much is being done for their children from a legal perspective.

My view is that the charitable and medical view of disability still overshadows society's perception of disability. From a social perspective, the way disabled person's concerns are addressed by the Trinidad and Tobago government is generally through financial or material aid particularly in cases of poverty. The system is also bureaucratic which sometimes leaves many mothers unable to access government grants. The grants can also be viewed by some mothers as a charitable enterprise, and some may not even wish to access them because of the associated stigma (Reitief & Letsosa, 2018). Therefore, while policies may appear as a form of positive action by the government, for mothers who parent disabled children, policies may mean very little unless they became law. Hence, without legislation, mothers may still experience the stigma and inadequate social support in raising their disabled children.

2.6 *Chapter Summary*

In this review, I examined the literature as it relates to the main aim of the study which is to explore the lived experiences of mothers who parent disabled children in Trinidad and Tobago with a view to understanding disability further. The review was framed in relation to the four research questions restated at the beginning of the chapter. I began with an examination of the definitions of disability followed by a closer look at the various models of disability. Then I addressed the research questions where I explored the experiences and perceptions of mothers of disabled children. First, I focused on the value and relevance of mothers' experiences, and second, I examined the perceptions of mothers of their role as caregivers to their disabled children. Finally, I explored mothers' perceptions of the government's role in caring for and educating disabled children, with a focus on Trinidad and Tobago. The next chapter will discuss the methodology adopted for this research.

3 Chapter Three - Methodology

3.1 Introduction

Good research is thorough, systematic, and rigorous. According to Sikes (2004) methodology are the theory of getting knowledge and the methods we employ to present data as evidence for the construction of knowledge about the phenomenon being researched. My choice of methodology was informed by the overall aim of the research which was to find out the experiences and perceptions of mothers who parent a child with a disability in Trinidad and Tobago. In presenting the methodological premise of the study, I will discuss the research design, the role of the researcher, participant selection, the methods or procedures employed, the data analysis plan, and the ethical considerations of this study.

Aims, Purpose, and Research Questions

In this research study, I have adopted the qualitative interpretive paradigm, as my study is aimed at exploring mothers' lived experiences in parenting and educating a child with a disability in Trinidad and Tobago. In undertaking this study, I aimed to represent three mothers who parent disabled children in Trinidad and Tobago and to gain an enhanced understanding of their perceptions and experiences. From the result of this research, I hoped to provide information that will allow policymakers to craft more inclusive policies for disabled children and their caregivers as well as change society's attitudes and perceptions about disabled persons. The four research questions sought to examine a) the value and relevance of understanding the lived experiences of mothers, b) how they perceive their roles in caring for their disabled children, c) how they view the role of the government in educating disabled children and d) explore the lessons one can learn from knowing about mothers' experiences and perceptions of disability in Trinidad and Tobago.

While there is research available on mothers of disabled children (Landsman, 2003; Runswick-Cole, 2013) I found no local research done in Trinidad and Tobago that focused specifically on this area of investigation. Hence, I aimed to add to this limited research by drawing on studies in disability and looking at the social and personal lives of the participants as well as the way they view their roles and that of the government in caring for disabled children. Therefore, to conduct this research and look at participants

in their local setting, hearing their voices and representing them through the stories they tell, narrative inquiry using storytelling was the most appropriate method.

3.2 Research Tradition

McCusker and Gunaydin (2015) purported that research is a “systematic and rigorous process” (p.541) used to explain phenomena through a quantitative, qualitative, or mixed-methods approaches of inquiry. These authors went on to say that quantitative research aims to classify, construct, and count statistical models when explaining observations. Alternatively, according to McCusker and Gunaydin (2015), qualitative methods generally aim to understand the experiences and behaviours of people. Therefore, whereas qualitative methods are concerned with understanding peoples’ experiences and finding out the “how,” “why” or “what” of a given phenomenon, quantitative methods answer “how many” or “how much,” (p.541). Additionally, in qualitative methods, the personality, integrity, and role of the researcher are more pronounced than in quantitative research (McCusker & Gunaydin, 2015).

3.3 Qualitative Research Designs

In qualitative designs, there are several approaches that can be used. Creswell (2013) cited five well-known approaches which included phenomenology, case study, narrative inquiry, grounded theory, and ethnography. My research sought to examine the lived experiences and the perceptions of mothers who parent disabled children in Trinidad and Tobago. Gaining an insight into the lives of these mothers meant listening to their voices and representing them through their told stories. Hence in my methods, I used a narrative approach to inquiry using the stories told by mothers as data for my study.

Denzin and Lincoln (2011) among other researchers agreed that narrative research belongs to the interpretive, naturalist approach to the world (Clandinin & Connelly, 2009; Kim, 2016; Patton, 2002). As a result, qualitative researchers study situations or people in their natural settings and try to make sense or interpret a phenomenon by the meanings people attach to them (Denzin & Lincoln, 2011). Qualitative data analysis involves interpretation which then affects how we represent the stories told to us as researchers. We analyse narrative data because we want to understand the meaning our participants give to themselves, their lives, and their experiences through the stories they tell (Kim,

2016). Therefore, narrative inquiry is a way of understanding experiences through stories people tell which in turn helps us understand the human phenomenon and human existence (Kim, 2016). Qualitative researchers achieve this through the choice of words or the use of language in interpreting the stories told (Clandinin & Connelly, 2000). In my quest to understand the social and personal experiences of mothers who parent disabled children, and from a philosophical position, the constructivism and interpretivism schools of thought were used to form the basis of my research analysis.

Justification for the Approach

In providing a rationale for using the qualitative tradition of inquiry, I have examined my ontological and epistemological assumptions for this research. Within these discussions, I have provided an insight into the interpretivist and constructivist theories as well as a justification for using narrative inquiry and storytelling for my research. Qualitative research falls within the realm of interpretivist philosophy. This type of research is complex because it involves interpreting human behaviour and interactions and finding meaning in human actions. For interpretivists, exact, methodical, and theoretical answers to complex human problems do not simply occur. As Clandinin and Connelly (2000) noted, for individuals, every situation or experience is different and unique and must be analysed according to the uniqueness of the contexts in which it is surrounded.

3.4 *Ontological Assumptions*

Interpretivist research is concerned with seeing reality as constructed from experiences of the social and personal lives of individuals. Chowdhury (2014) discussed that interpretivism views the world where reality is socially constructed. Interpretivism considered as a branch of idealism emphasizes the meanings people ascribe to social and cultural life. This branch of philosophy was heavily influenced by the teachings of German sociologist, Max Weber (Chowdhury, 2014). Weber promoted the philosophy on "*verstehen*" (p. 435) which means *understanding*. In short, his idea was to understand and have empathy for participants. It reminds me of my high-school literature novel, *To Kill a Mockingbird* by Harper Lee (1960). In this book, the father-figure character, Atticus, advised his children that to understand someone else's perspective, the best way, figuratively speaking, was to get into their shoes and *walk around*. In other words, it is

not enough to just listen to what people say or to judge what they do, but we should strive as much as possible, to understand as many aspects of their lives as possible and the attached meanings in relation to the context of their stories being told. In this research, having an idea or generalizing about mothers' experiences of caring for disabled children is not sufficient to understand the many facets of their lives. One-to-one relations, personal contact, being invited into their spaces or homes, and reliving significant moments of their deeply personal stories together, may provide a broader insight into their perceptions and can create a better understanding of their experiences.

Interpretivism looks for the meanings people ascribe to experiences and hence believes that unlike the positivist tradition, which subscribes to one reality that is *out there* to be discovered, there are multiple realities and truths as seen through the eyes of people being studied (Chowdhury, 2014; Sikes, 2004). The realities of the mothers in my study were unique to their personal, social, and cultural circumstances although they all shared a common factor of parenting disabled children in Trinidad and Tobago. Hence their stories would have different connotations for their given realities or truths.

3.5 Epistemological Assumptions

In research, positivist or interpretivist, the goal of achieving absolute truth is unattainable. If the researcher believes that knowledge is “real” or “out there,” then methods such as observation or quantifying methods would be more suitable (Antwi & Kassim, 2015; Patton, 2002; Sikes, 2004). However, if the researcher considers knowledge to be subjective and experiential, then getting the perceptions of the participants involved will be an important feature. The truth, therefore, for everyone will be different as it will be based on their distinctive set of lived experiences. Therefore, social reality will be based upon an individual's ideological position (Chowdury, 2014) and the norms and values one holds. Their truth will be relative to the knowledge they gain from personal or life experiences and their “social positioning” (Sikes, 2004, p. 22) or what Clandinin and Connelly (2000) described as “experiential knowledge” (p. 3).

Knowledge is resultantly acquired from personal experiences and constructed from the inside rather than imposed from the outside. In other words, truth and knowledge come from an individual's subjective experiences on how he/she construct meaning from

relations with others. Reality is therefore multifaceted and complex, being a phenomenon that can have multiple meanings and interpretations (Clandinin & Connelly, 2000). Thus, research that takes the view that knowledge is based upon experience and is therefore subjective, will emphasize the accounts given by the participants (Moen, 2006; Sikes, 2004). For this reason, the stories that people tell, mothers in this instance, the perceptions they share of their lived experiences, and the interpretations done by the researcher are important components of narrative inquiry.

3.6 Narrative Inquiry

According to Clandinin and Connelly (2000), doing narrative inquiry is paramount to representing and understanding experience (p. 18). They agreed that narrative inquiry is a way of inquiring into experience through “collaboration between researcher and participant, over time, in a place or series of places, and in social interaction with milieus” (Clandinin & Connelly, p. 20). These words, I think, capture the essence of narrative inquiry as they are concerned with how people extract meaning from the daily experiences of their social and personal lives.

Moen (2006) posited that narrative inquiry can be considered a frame of reference and a means of reflection, a method and a way to represent the study. To this end, Moen agrees with Clandinin and Connelly (2000) who noted that narrative thinking and narrative method are a part of the phenomenon of narrative. Thinking narratively is part of the experience of narrative inquiry since the researcher becomes part of the experience under study. Clandinin and Connelly went on to indicate that John Dewey’s philosophy viewed experiences as both social and personal. They concurred with Dewey, a renowned education philosopher, that experience is situational, relational, and, temporal, and those who undertake narrative inquiry can reflect on and reconstruct experiences, a state which “has the potential to reveal the construction of identity, knowledge, and the humanness of care” (Lindsay & Schwind, 2016, p. 14). Since my research sought to examine both the perceptions and experiences of the mothers who parent disabled children in Trinidad and Tobago, narrative as a methodology was the most appropriate approach to address the research questions and achieve the aims of the research, which broadly seek to increase understanding of disability from the perspective of mothers. In my opinion, the value and relevance of experiences should not be taken for granted or understated in any way, because each person’s experiences are different and can provide insights into

understanding a phenomenon in a different way. In using a narrative methodology, I focused on storytelling as a method of inquiry.

3.6.1 *Storytelling*

In life's journey, there are many experiences and dialogic interactions (Moen 2006) within our personal and social environment. These experiences are combined into what makes up our lives which can be overwhelming and complex at times. This complexity of experiences can be organized or "ordered," in a structured way into a "meaningful unit" such as a narrative or a story (Moen, 2006, p. 56). Aptly, storytelling is a natural way of recounting experiences (Clandinin & Connelly, 2000; Sikes, 2004).

Neile and Novak (2013) reckoned that storytelling is a *folk-art* and, as such, must be interpreted as any other art form. Education or the acquisition of knowledge seeks understanding, which in turn, is derived from analysing and synthesizing experiences which are common elements of storytelling itself (Neile & Novak, 2013). The storyteller, in attempting to understand tries to transfer the meanings of these experiences to the listener by using words or language. In narrative inquiry, the researcher and participant are both storytellers in their own right; the researcher retells the "told stories" (Clandinin & Huber, 2002) of his/her participants, and at the same time, tells his/her own story through his/her writings. Since the researcher uses language to transfer this knowledge, storytelling is based on interpretation. However, stories are not sequestered entities but must be understood in relation to the cultural context of the individual who tells them. In this way, human knowledge is constantly constructed or reconstructed (Moen, 2006) which buttresses the view that human understanding and knowledge are relative and by large, socially constructed. The acquisition of new knowledge is therefore dependent on one's past and present experiences, one's values and relationships with others as well as the place where the stories are being told (Moen, 2006).

In telling their stories, people usually describe their experiences as moving through different times in their lives. They rarely follow a chronological order in recounting experiences (Clandinin & Connelly, 2000) as they go back and forth in time. The researcher becomes involved in this temporal nature of the narrative as their participants move around with their experiences, and as both researcher and participant attempt to interpret and understand the meanings attached to experiences. Hence the

researcher may adopt the position of observer, participant, observer-participant, insider, outsider, or insider-outsider. In other words, the researcher becomes “part of the parade” (Clandinin & Connelly, 2000, p. 61) in narrative inquiry. I experienced this temporality while conducting the interviews with each of the three mothers as they spoke about their perceptions and their personal and social experiences involving their disabled children. They spoke about their past experiences, their present realities, and their hopes for the future. Clandinin & Connelly (2000) described this temporality as one of the three “commonplaces” of narrative inquiry. The other two were “sociality” and “place.” It is in these dimensions where the researcher usually situates him/herself, “in the midst” (p. 72) in order to understand and construct narratives (Guyotte, 2015).

These commonplaces that Clandinin and Connelly identified, I found were an interesting aspect of storytelling. The meanings the mothers ascribe to their experiences moved both of us (researcher and participant) through space and time. They brought me as the researcher into their personal space, their social experiences, and literally into their physical places or homes, making me become part of the experience itself, part of the phenomenon being explored. The knowledge gained from the mother’s stories and their interpretations made the reality of my own experience in this narrative inquiry worthwhile and meaningful. Further, I found myself creating new knowledge for myself as I learned about disability from my participants’ stories. My own perceptions about mothers and disability began to evolve and adopt a different lens as I conversed with the participants. Beyond that, it made me reflect on my role as a researcher from the position of an insider-outsider researcher (Hockey, 2006; Helawell, 2006; Merton, 1972).

3.7 Role of the Researcher

In this research study, I have adopted the narrative approach, as my study is aimed at exploring mothers’ perceptions and their social and personal experiences in parenting and educating disabled children in Trinidad and Tobago. In narrative inquiry, the position the researcher adopts is important as he/she can be privy to sensitive data from participants (Greene, 2014). I took the position of an insider-outsider researcher for my research.

Insider researchers, on one hand, are considered to be part of the community within which they are researching while outsiders are considered to be outside of the

group they are studying (Hellowell, 2006). On the other hand, insider/outsider research should be seen at best as a continuum rather than dichotomous (Hockey,2006). Hellowell agreed with Hockey when he said that “ideally the researcher should be both inside and outside the perceptions of the researched” (p, 487). He also cited Hammersley (1993) as saying that a degree of “empathy and alienation” are useful qualities for a researcher in conducting insider/outsider research (Hellowell, 2006, p. 487), as there are elements of “insiderness” and “outsiderness” on the two dimensions of research. In this research elements of, my “insiderness” is reflected in being a woman who is researching other women and a mother who is researching other mothers. Additionally, I am a Trinidadian who, like my participants belong to the same society and probably have similar experiences with encountering outsider perceptions about childhood disability since my profession is an educator dealing with small children for over thirty years.

In this research also, the participants were all women of an East Indian background like myself and which was unintentional and unplanned. A full description on the selection of participants will follow later on. The point here is that coming from a similar ethnic background I would have had some knowledge and understanding of the culture, values, and upbringing. Hence, in all these respects, I am a member of the community to which my participants belong. We share a historical background, “an identity, language, and experiential base” (Dwyer & Buckle, 2009, p. 58). However, Hockey (2006) was of the view that working with one’s own society, and specifically with one’s own ethnicity with a common heritage is “perilous and much more difficult” (p. 211) although there is a validity and value that may not be otherwise easily obtainable.

Some of the advantages of insider researcher can be summarized as (1) the ability to possess “*a priori* intimate knowledge of the community and its members” (Merton as cited by Hellowell, 2006 p. 484); and (2) the ability for the researcher to be accepted by participants more rapidly and completely thereby creating an avenue for greater depth of data gathering (Dwyer & Buckle,2009). Hockey summarized the advantages of insider researcher concisely:

“The advantages of researching in familiar settings, for example, the relative lack of culture shock or disorientation, the possibility of enhanced rapport and communication, the ability to gauge the honesty and accuracy of responses, and the likelihood that respondents will reveal more intimate details of their lives to someone considered empathetic are juxtaposed with the problems that proponents of insider research nevertheless acknowledge” (Hockey, 1993, p. 199).

However, Hockey warned against certain pitfalls in doing insider research. He claimed that first, the researcher should be aware of the tendency to be biased; second, over-familiar use of language where the researcher can overlook key terms used by the participant; third, taken-for-granted cultural orientations; and finally, the potential discomfort of the participant when the researcher asked questions that the participant may feel the researcher should know the answers (Hockey, 1993) and which can distort the researcher/ participant relationship.

My “outsiderness” relates to the fact that I do not parent a child with a disability. Hence, I am an outsider who is not a member of that group. However, there are advantages to being an outsider. Hellowell cited Burgess as saying that an outsider, gives the researcher “scope to stand back and abstract material from the research experience” (p. 485). It becomes easier for the researcher to critically “observe events and situations which the insiders may take for granted as unquestionable truths” (Hellowell, 2006, p. 485). So for me, not having a child with a disability, offered me the opportunity to see first-hand, the experience of the mothers and to look objectively as much as possible, into their lives, and tell their stories as they recounted. Another view was taken by Hellowell on being both insider, and outsider, which is the position I took for this research. He said that being an outsider or an insider exclusively does not mean that findings are not valid. He cited Martin Hammersley as saying that generally, the validity of the findings is enhanced “by a judicious combination of involvement and estrangement” (Hellowell, 2006, p. 485). In other words, depending on the purpose of the research, and its objectives, being an insider/outsider researcher has validity in its findings.

In my dual role as insider/outsider to the group I studied, and in the journey of this research, I asked myself, why did I choose to study this area of research? Why do I want to find out about the experiences and perspectives of mothers who care for disabled children? I realized ever since I was a teenager that I considered persons with a disability, particularly disabled children, as difficult to manage. As an adult woman and a mother, I wondered how mothers cope with their disabled children, who, in my eyes, did not fit the criteria as *normal*. How do mothers feel to send their disabled children to “special” versus “normal” schools? As an administrator of an educational institution, I observe first-hand the struggles that mothers take upon themselves to educate their children with an

impairment or a disability. I remembered while growing up, my aunt had a daughter, I will call her Anita, who had a speech impairment and also had delayed cognitive and mental development. I distinctly remembered how everyone felt sorry for my aunt and used to laugh pitifully at Anita in many instances. Even though she had many siblings, in retrospect, they all seemed ashamed to be seen with Anita. Further, I have never seen Anita's father taking her anywhere. It was as if my aunt was the sole caretaker or the "owner" (Jeske, 1996) of her child. My aunt took Anita everywhere she went. I even heard adults saying that anywhere the mother went she had to *drag that child*, Anita, along, and sometimes they will not invite her because she will carry Anita with her. As an outsider researcher, I do not have a child with a disability, so I cannot *know* how to experience motherhood caring for such a child. However, as an *insider-mother-researcher* (my term), I was made sensitive to the mothers' experiences and I tried to see life through the stories they tell me.

In reflection and as a mother myself, I wondered how the world of a mother like that of my aunt, differed from mine. I wondered about equal treatment, children's rights, and protection for disabled children. I thought about how they manage with their disabled child with little or no social support. I wondered how single mothers who fell within the lower income bracket, afford medical care and education for their children who may be both ill and disabled. I had a particular experience with one of my participants who at the time was someone I barely knew. Her son had a seizure at school, and I saw how she forgot everyone and everything momentarily and focused totally on him. At that time, from the way I saw it, the world could have stopped spinning, because, at that moment, nothing else mattered to her except her son. It was the first time in my thirty years of being an educator that I saw that display of unconditional motherly care delivered to a child in a school environment without the care of what anyone else may think.

This incident made me question a lot of things about what we know about the world of a mother who cares for a child with a disability and about her role as a primary caregiver (Collins & Coughlan, 2016; Landsman, 2005). It made me think about what goes through her mind in caring for her child without adequate support or lack of understanding of her insurmountable challenges. More than that, I think of the curious stares and the projected pity mothers of disabled children may have encountered, the "talks" behind their backs and the laughter of other children maybe, and I question myself

about what we know of their lives to make any judgements of how they raise their children. I have encountered persons in the bus, the malls, and on the streets, getting annoyed when mothers had children whose behaviour was uncontrollable because they had a communication disability; and I painfully admit, I was once, one of those persons. I still carry that guilt with me for treating children harshly when I was a young educator, because of my lack of understanding of mental or behavioural problems in children. These are some of the instances and thoughts that focused my interest in this area of research. I wanted to know and understand the mothers' stories, their experience, their perspective, and their voice as it regards caring for their disabled children. I felt that much was not known about these kinds of "real-life" experiences, particularly in the area of disability in Trinidad and Tobago. Listening to the mothers tell their stories elucidated for me, a world of experiences, I never had. In my doctoral journey, however, the issue of the power relations on the research process was also an important consideration.

Clandinin and Connelly (2000) said that the relationship with participants is a "tenuous" one always "in the midst" to be negotiated (p. 72). As narrative inquiry is relational, there will always be tensions. These authors advised that as researchers in this field it is inevitable that we become involved with our participants and at the same time we have to see our stories, the participant's stories, and the larger landscape in which they live. Therefore, narrative inquiry allows for a kind of intimacy with participants because of the sensitivity of experiences shared. In my role as researcher, I had to be mindful of the type of relationship I had with my participants as it could indicate an ethical dilemma with reference to power relations and biases that can get in the way of data gathering and analysis (Hockey, 2006). Two of my participants were mothers of the Centre which I manage, so we had a professional relationship. However, in approaching them to be a participant in this inquiry, it was important to gain mutual trust. I had to ensure that confidentiality exists on both of our parts and that information I gave of myself will not be divulged as it can compromise my job. Also, the mothers had to trust that what they told me will not be shared in any untoward way, as we both knew people in common. The other participant was a distant relative. I knew her for a long time although not in a familiar way.

After the data-gathering exercise, I developed a more familiar relationship over time with all of these individuals and they came to regard me as trustworthy and non-

judgmental (Shenton, 2004). This is what Lincoln and Guba (1986) called prolonged engagement; where adequate understanding will create a relationship of trust between the researcher and participants and where the credibility of data will be maintained. Additionally, I had to be mindful that the participants did not think they were obligated to participate in this research. In other words, because I am the manager of the institution for two of the participants and a distant relative to one, I did not want them to feel they had to comply with my request for any reason. I made it known to all participants that participation was strictly voluntary and they have the right to withdraw at any time and according to Shenton (2004), “they should not even be required to disclose an explanation to the investigator” (p.66). They understood and were still willing to participate. I also did not know much of the home situation of any of these mothers, so personal biases or judgements of their lifestyles were very limited on my part. However, more about the selection process will be discussed in the following section.

3.8 Participant Selection

Creswell indicated that data collection comprises more than just the type of data and procedures for collecting it. It involves a range of actions such as obtaining permissions, sampling strategies, finding ways to record information, data storage, and considering ethical issues (Creswell, 2013). In the collection of data for narrative inquiry, he indicated that researchers could engage with either individuals or a group. I chose to sample individuals for the selection in my study.

3.8.1 Purposeful Sampling

There are several ways to collect data and various approaches to select a sample size. In this research, I used purposeful sampling. Creswell said that in narrative studies, there should be one or more persons who are accessible and are willing to provide information for the study. Such persons can be categorized, according to Creswell (2013), as a “marginal” or “great person” or an “ordinary person” who can act as an example of a larger population (p.150). In my research, I used the “ordinary person” as they all had a story to tell, which Creswell calls “first-order narratives” (Creswell, 2013, p.151). He indicated that in narrative sampling the researcher reflects on whom to sample or who is “available” and in this case who can “inform an understanding or provide insightful information” of the dominant phenomenon being studied which he identified as

purposeful sampling (Creswell, 2013, p 155-156). I chose this sampling method as it gives a deeper insight into the research problem, its questions, and the fundamental phenomenon in the study.

I had gone through several attempts to source individuals who would be willing to tell their stories about caring for a child with a disability in Trinidad and Tobago. However, not many responded positively. Originally in this research, I intended to interview five mothers as a sample size. However, this posed a greater challenge than I anticipated, as persons who did not know me were not willing to share their stories with me. Sometimes, researchers have to be “flexible” as “sampling can change during the study” (Creswell, 2013, p.157). This is what I experienced in my research when I had to change from five participants to three to proceed with my research. However, three participants were appropriate for my research as the intent was not “to generalize the information” (Creswell, 2013, p. 157) but to collect extensive details about the individual being studied. My participants can be considered a minority group in society as they fit the category of being both females and mothers of disabled children. I felt hearing their voices and listening to their stories can provide insightful information of how they think society, in general, perceives persons or disabled children and their caretakers.

3.8.2 *The Participants*

The participants in my study comprised three mothers who parent disabled children in Trinidad and Tobago. I mentioned previously that I went through several attempts to contact persons to consider being a participant in my study. Since I worked in the Ministry that deals with disabled persons on a national level, I went to this source first. There I got a list of fifteen persons who were the biological mothers of disabled children. From that list, I was able to contact ten persons. After the telephone conversations, seven agreed to meet for an interview. However, some of them kept cancelling or did not respond to my messages. Finally, only two agreed, these two had children who attended the Centre where I work. So they knew me in a formal capacity. The third participant was a distant relative of mine who knew of me, but we were not in close contact. I knew she had a daughter with a disability. When I contacted her, she agreed to do the interview. It was coincidental that all participants lived in central Trinidad and were all of East Indian descent. Table Two (2) gives a profile of the

participants for this study. Participants were chosen based on certain criteria. They had to first, be the biological mother of the child; I choose to take the birth mother and not an adopted caregiver or grandmother because of the notion of *creating or “owning”* a child with a disability discussed in Chapter Two (Jeske, 1996) and the stigma and isolation attached by *not making* a “perfect” baby (Landsman, 2005; Lalvani, 2011). Second, the child had to have a diagnosed medical condition or an impairment that renders the child disabled, and third, the child had to be of school-age or older being cared for by the mother.

Getting people to share their personal experiences, I found, was not something to be taken for granted. Sometimes people are careful about to whom they divulge information especially if it concerns the protection and identity of their children. The issues of labelling and stigma attached to disability (Asa, Fauk, Ward, Mwanri, 2020; Landsman, 2005; Goodley, 2011) also could have been factors that contributed to persons being unwilling to be a participant in my study, especially where the researcher was unfamiliar to them. The participants who agreed to be in my study, in one way or the other knew me and had brief or professional (formal) contact with me. It seemed therefore that for the mothers to be comfortable in sharing private and sensitive information for this research, they wanted to know and feel that it was safe to confide in the person who was conducting the research. As a result, only three mothers agreed to be interviewed for this research. A description of their profile is included in Table Two below.

Table 2 – Participants Profile

PARTICIPANT'S NAME	AGE	ETHNICITY	AGE OF CHILD	NAME AND SEX OF CHILD	TYPE OF DISABILITY	ECONOMIC/ SOCIAL STATUS
Ana	45	East Indian	10	Male (Kris)	Seizures and Delayed cognitive development	Middle income Lives with husband Only child
Sherma	70	East Indian	40	Female (Val)	Severely delayed development	Middle income Husband diseased Three children
Prabha	52	East Indian	26	Female (Kate)	Mute Profoundly deaf	Low income Single Parent Only child

3.9 Procedures

Various authors (Clandinin & Connelly, 2000; Denzin & Lincoln 2011; Creswell, 2009; Patton 2002;) cited several forms of *field text* or data collection procedures in qualitative inquiry. While there may also be several forms of emerging techniques, Creswell (2009) organized data collection procedures into four categories; observations, interviews, documents, and audio-visual materials. The main procedure involved in this research was personal in-depth interviews with the participants. I also used notetaking to record data. This was then followed by recording, transcribing, and reviewing the data before analysis was carried out.

3.9.1 Interviews

The purpose of interviewing as Patton (2002) indicated is “to allow us to enter into the other person’s perspectives,” to find out what is in their minds, and “to gather their stories” (p.341). Interviews provide researchers with rich and detailed qualitative data for understanding participants’ experiences, how they describe those experiences, and the meaning they make of them (Castillo-Montoya, 2016; Rubin & Rubin, 2012). The core of interviewing in qualitative research is an interest in other people’s stories because

I strongly believe that we must value people's lives because of the worth they have. Hence, I tried to approach inquiring into the participants' lives with care and sensitivity (Castillo-Montoya, 2016; Rubin & Rubin, 2012) as much as I could.

This research is narrative in nature and utilized personal in-depth interviews as the main primary data collecting procedure. Following ethical clearance given by the University of Sheffield. I requested a meeting with the participants to discuss the research and the interview process. As advised by Chenail (2011) before the interview I reviewed the consent form and noted any unclear or confusing passages before signing and doing the recording. When there was a final agreement, an interview was scheduled with each participant at a date and time convenient to her. The procedure for the interview was discussed. Each participant was given an information sheet detailing the research, its purpose, timeframe, what will be required of them, and an agreement to be audio-taped. This was one way of ensuring informed consent (Lad & Dahl, 2014). After the relevant forms were signed, the interviews followed at the selected places on the agreed date. In choosing the areas to conduct the interview, several factors had to be considered. The location had to be quiet, mutually agreed upon by the participant and myself, and have no noise that will affect the audio recording or the quality of the interview. For two of the participants, the interviews were done at their homes. The third was done in my office as the participant wanted it that way. The participants were then audio-taped in a quiet setting. The interviews were unstructured with a few guided questions. Some notes were taken to support primary data collection. Audio recording, transcribing, reviewing, and thematic analysis were done following the interviews. A mutual agreement was established for a further interview if required.

In conducting the interviews, I tried not to have leading questions. However, there were times I had to focus participants on the research at hand to get them talking. This was usually at the beginning of the interview. After that, there were just some clarifying questions I would ask, and for that I used open-ended questions. According to Mack, Woodson, MacQueen, Guest and Namey (2005) open-ended questions give participants the opportunity to respond in their own words and are "meaningful and culturally salient to the participant, unanticipated by the researcher, rich and explanatory in nature" (p.4). In preparation for the interviews, I had five to eight questions I wanted to ask each participant at various points in the interviews.

Some of the questions were used to initiate and promote the conversation when there were points of lapses in the interviews (Castillo-Moteyo, 2016; Janesick, 2011). However, during the interviews, I found that although I had planned some of the questions the participants did not adhere to answering all of them when I asked them. This happened with all three participants but in varying degrees. The reason, I think, was that when the participants became comfortable with me, they seemed to forget about the formality of being interviewed and became immersed in their own stories. They seemed almost happy to recount their experiences as it involved voicing their feelings, their struggles, their conquests, their pride, and efforts for their children.

I believe that the level of trust the participants developed for me during the course of the interview was a factor that spurred them on to share private thoughts and experiences. One of the mothers even offered to assist me with my thesis by writing for me if I needed the help. I was very moved by this act of kindness but politely refused, telling her it was not something that could be done. So, I listened. I took note of how the degree of comfort in speaking about their very innermost thoughts and feelings changed from being careful to being trusting as we draw to the end of the session. This brings to mind what Stuckey (2013) referred to as an interview being an “inner-view... a way for researchers to understand the thought process that exists inside, an inner look at why people behave in the way they do” (Stuckey, 2013, p. 56-9). I had to deviate from my method of using pre-planned focused questions to an almost unstructured, conversational interview, which meant that sometimes I had to “go with the flow” (Patton, 2002, p.342). I realized during the interviews that all three mothers were not interested in all of my well-structured questions, they were more interested in sharing their experiences. In this way, the information gathered yielded a thick rich description of the lives of the participants (Geertz, 1973). Overall, interviews were the best data collection tool as I obtained first-hand raw data about the lived experiences of the mothers which were used to answer the research questions.

3.9.2 Notes

I did not do observation as a formal exercise during the interview, but I did make mental notes throughout, especially when the mothers were emotional. I would, therefore, not refer to my notes as *field notes* in the usual sense of the word. Field notes refer

to qualitative notes documented by researchers during or after observing a specific phenomenon that they are studying (Clandinin & Connelly, 2000; Denzin & Lincoln 2011; Creswell, 2009; Patton 2002). The notes I took allowed me to record what I observed in an unobtrusive manner (Stuckey, 2013).

I found it was best to record notes instantly after leaving the participant so that important details will not be forgotten and eliminated. Throughout the interview, I took a mental note of the participant's actions, body language, voice and intonation, and emotional state. For example, one of the mothers was very emotional in re-telling her experiences. I asked if she would like to stop the interview, but she said no, she was happy to share her memories. I felt that writing while they were speaking would create an onerous formality to the interview or it may create discomfort for the participant (Patton, 2002, p.343). I also sensed that it was precisely this informality throughout the interview that had the mothers speaking without much reservation. As soon as the interviews were finished, I made my notes so I would not forget (Patton, 2002).

Stuckey pointed out that one major disadvantage of notetaking is the conscious or unconscious bias of the observer (Stuckey, 2013). However, to mitigate this effect of bias, I listened to the recordings repeatedly to thoroughly familiarize myself with the data. Although the recording can be replayed to listen for errors, pauses, or silences, the combined expression and gestures gave a better indication of how strongly the participant felt about particular situations or people (Patton, 2002). For example, there were instances that mothers were driven to tears in relating their experiences and one of them became very angry and pounded the table with her fist when describing a particular incident.

3.9.3 Recording, Transcribing, and Reviewing

Audio recording which is the taping of sounds or voices using an electronic recording device was used as a method of collecting first-hand primary data. I used a Samsung tape recorder to record the interviews. After recording, I backed up this data on a mobile storage device in case of loss or theft or in the event one device malfunctioned (Janesick, 2011, p. 103). The recording was immediately encrypted so that no one would be able to access it. It was kept in a locked cupboard for safe-keeping. I ensured

participants that after the thesis writing, their information will be destroyed. The recording was followed by transcribing the data before analysis.

Transcription, an essential process in qualitative data analysis is “rendering recorded speech in writing” or an exact replication of words recorded, and which is important for informed consent (Lapadat & Lindsay, 1999; Denzin & Lincoln, 2011; Poland, 1995). In other words, it entails verbatim transcriptions that capture both the meaning(s) and perception(s) or the recorded interviews discussions as well as the context in which they were created (Lapadat & Lindsay, 1999). Audio transcription was used in this study. My experience with transcribing is that it was a tedious and time-consuming process. However, it allowed me to become acquainted with the data. For this research, it took a total of thirteen hours to transcribe one and a half hours of conversation. This time taken did not include listening for corrections which took another three hours. I listened to each recording five times which got me very familiar with the data. In periods of doubt, I also had to go back and verify the transcript with the audio recording that took additional time. Transcribing and reviewing the data led to greater accuracy for the process of analysis. It was one way to establish the trustworthiness of the transcribed data that appears to be an important element of rigor in qualitative research (Poland, 1995). In reviewing the data collected, I listened and doubled checked the recording for accuracy. That is, I checked for pauses, grammar, omissions of words or sentences, laughter and periods of silence. This process was followed by then reviewing the transcribed data for codes and themes in relation to the research aims of the study, which will form the analysis of the data.

3.10 Limitations

Limitations are constraints that are above one’s control. This study is limited in two areas; socio-economic background and sample size and of participants.

Socio-Economic: Two mothers were single mothers by being widowed. One of the widowed mothers had other children who did not have any disabilities. Two mothers had an only child, which is the child with the disability. Two mothers had female disabled children and one mother had a male. Two mothers can be categorized as middle income, and one as low-income based on the standard of living and income level. Their financial status was revealed to me, but because of ethical concerns, I cannot divulge that

information. None of the participants represented the high-income bracket or wealthy mothers.

Sample Size: There are only three participants in this study. As such it may be insufficient to represent a wide cross-section of mothers in Trinidad and Tobago. In-depth interviews were conducted to get sensitive data. Although the number of participants was small the quality of data was an important factor in this research and was sufficient for the purpose of this study. Sample size, however, was discussed at length earlier on. Another limitation can be seen in the cross-section of the participant. All were of East Indian descent and therefore, had similar cultural backgrounds. This limitation was due to the inability to find participants who were willing to participate in the study of this nature, and can potentially limit the findings of the data. Proceeding on, I will discuss the data analysis plan, trustworthiness of data. and ethical concerns in this narrative study.

3.11 Data Analysis Procedures

Data analysis in this research is concerned with using the raw data to generate meaningful insights from the stories of three mothers who parent disabled children in Trinidad and Tobago. In my research, I used interviews as the main data gathering procedure. Therefore, I used mainly primary data collection. Some notes were taken during the interviews to remind me of certain types of information that would not have been able to be audio recorded, such as emotions displayed by participants at the time of the interview. The interviews conducted focused on finding out first-hand information from the participants through their told stories about their experiences. In gathering sensitive data, the use of in-depth interviews for data collection was the most appropriate for the purpose of this inquiry.

3.11.1 Research Questions and Coding

In answering the research questions, I employed thematic analysis developed by Clarke and Braun (2014) and Pope, Ziebland, & Mays (2000). The objective and purpose of this research are to find out and to have a greater understanding of the perceptions and experiences of mothers who parent disabled children in Trinidad and Tobago by listening to the stories they tell about their lives. In this study, I used qualitative research methodology. Since this approach demands that I be *in the field* collecting the data, it was

difficult to avoid thinking about what is being heard and seen (Pope, et al., 2000). In other words, I would have already begun analysis of the data whilst in the field. This research used an inductive approach to analysis meaning that categories and themes were gradually obtained from the data vs a deductive approach where either at the beginning or partially through the analysis was used to approach the data. I used mainly Braun and Clarke's Thematic Analysis with some referencing to the Thematic Framework of Analysis designed by Pope et al. (2000).

Braun and Clarke's (2012) approach to coding involves a (recursive) six-phase process: familiarization with the data; generating initial codes; searching for themes; reviewing potential themes; defining and naming themes and producing the report. I also referred to some aspects of Pope et al. (2000) Thematic Framework of Analysis as I felt some of their processes were appropriate for my analysis. Similar to Braun and Clarke this involved familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation.

Qualitative analysis can pose a challenge as it requires placing the raw data into logical, meaningful categories. This type of analysis also means that the researcher has to examine the data in a holistic fashion and find a way to represent the interpreted information as close as possible to the raw data before communicating it to an audience. In my research, there were four iterations done to arrive at the final themes. First, I combed through the data line by line from the participants' interview transcripts and extracted salient ideas or concepts. These were placed into initial codes. Second, I condensed these fifty-seven codes into larger chunks of relevant data where twenty-nine codes were then placed under broad headings. The headings were gleaned from going through the data meticulously and looking for patterns, repetitions, and salient or unusual bits of information. I ensured that I accounted for all the usable data (Saldana, 2016) received from participants. From these headings, I further regrouped the data into twelve broader themes. Finally, I settled with four themes that I felt captured all the relevant data from participants. There were no discrepant or negative cases (Shenton, 2014) neither did I use any software for analysis. The process of coding, categorizing, and generating themes was very time-consuming, but it allowed for a detailed understanding of the data.

According to Clarke and Braun, (2014) a good Thematic Analysis is more than only reporting what is in the data; it involves aligning the research questions to the data to tell an interpretative story (Clarke & Braun, 2014). Pope et al. (2000) also believed that coding and categorizing data in thematic analysis is not just a simple process but must be well articulated and systematic in its approach. They stated that a key point is that the process is inclusive; categories are constantly added to reflect the many nuances in the data.

Familiarization

The first phase of Thematic Analysis that is common to all forms of qualitative analysis, is *familiarisation* with the data. That means I had to immerse myself in the data by reading and re-reading each and every data item and listening to any audio data at least once. In this case, I listened to each recorded interview ten times in order to get intimate with the data *inside out* (Clarke & Braun, 2014). Pope et al. (2000) also called this process indexing.

Generating Codes

Braun & Clarke's (2012) familiarisation process is followed by systematically coding the data to produce initial codes or labels that captured points of interest in the data that are meaningful. In my analysis, which was an iterative process, I reviewed each transcript at least twenty times. The data relevant to each category were identified and examined using a process called constant comparison (Pope et al., 2000) where I checked or compared each item with the rest of the data to establish analytical categories or specific codes. I then listed all codes and looked for ways to link them into larger chunks which will later become a theme relevant to the research questions. It was a rather lengthy process to structure the data into meaningful categories. First, I coded each line or paragraph for each participant. Then I cut and pasted each participant's response that fell under the same code onto a table to organize the data. I ensured that each line, was captured, regardless of how insignificant it may seem. Of course, there are some data in the transcription that could not be coded. This is what Phillip Burnard (1991) cited Field and Morse (1985) as calling *dross* which denotes the unusable *fillers*, such as "umm," "hmm" and "ah" in an interview that are unrelated issues to the topic being discussed.

Searching for Themes

The third phase in my analysis is searching for themes or “collapsing” the codes. Some themes can be hidden and cannot easily emerge from the data. Hence the procedure of constructing themes is not a passive activity, it is systematic and rigorous, and therefore a prolonged and laborious process (Clarke & Braun, 2014). Following these frameworks in my analysis, I found that the themes I expounded on were actually common to all three participants. However, the time or extent they spent talking about them was different for each participant. Hence, the process was rigorous and systematic and it established valid and trustworthy data and findings. Reviewing themes is the fourth stage in Clarke and Braun’s (2014) Thematic Analysis. According to Clarke and Braun, following the reviewing of the themes is the production of the report, which is in effect what will be done for the analysis in chapter four that follows. At this point, however, I will now turn to look at the trustworthiness of the data collected.

3.12 Issues of Trustworthiness of Data

In qualitative research, the trustworthiness of data is a crucial element in the analysis. While quantitative research capitalized on the reliability and validity of data (Creswell, 2013; Denzin & Lincoln, 2011; Patton, 2002) qualitative inquiry concerns itself with the trustworthiness and/or rigor in data analysis (Guba and Lincoln, 1986). In this regard, I will be using Guba and Lincoln’s framework in discussing the trustworthiness of data for my research. These authors identified four main areas. These include credibility transferability, dependability, and confirmability. According to Guba and Lincoln, (1986), these four terms were supposed to be the qualitative equivalents for validity and reliability, objectivity and generalizability in the positivist tradition.

Credibility refers to the confidence or believability of the findings of the data and the interpretations of them (Lincoln & Guba, 1985) to external readers. Credibility enhances the quality of the research (Patton, 2011) and involves strategies such as triangulation, prolonged contact, member checks, saturation, reflexivity, and peer review (Creswell, 2013; Denzin & Lincoln, 2011).

Transferability is the extent to which qualitative findings are applicable to other settings. Lincoln and Guba (1985) noted that the researcher’s responsibility is to provide sufficient descriptive data that readers can apply in other contexts; this is why thick

description is necessary in order for readers to make a transfer or a conclusion about the data.

Dependability refers to the stability of data over time and over conditions. In other words, can readers depend on the findings if applied to similar contexts? The dependability reinforces the credibility of data. Some research use strategies such as audit trails and triangulation. In this research, I used thick rich descriptions (Geertz, 1973; Guba & Lincoln, 1986).

Confirmability is ensuring that the data is accurate, relevant, or meaningful. This criterion is concerned with establishing that the researcher's interpretation of the data and findings accurately represents the participants' voices. Therefore, confirmability requires that the researchers "demonstrate how conclusions and interpretations have been reached" (Nowell, Norris, White & Moules, 2017, p. 3). Strategies such as reflexivity can be used to establish confirmability (Guba & Lincoln, 1986).

Authenticity- Apart from Guba and Lincoln's strategies, there is also a fifth criterion, called Authenticity which is exclusive to constructivist inquiry and has no parallel in the quantitative paradigm (Krefting, 1991). Authenticity refers to the extent to which researchers attempt to show multiple realities. A research paper is authentic if it projects the lives of participants as lived. Further, the research invites readers into a vicarious experience so that they become sensitive to issues being discussed with a greater chance of understanding the experiences and lives of participants involved in the research. Authenticity involves an evaluation of the meaningfulness that can result in social change from the narrative processes (Shannon & Hambacher, 2014).

Positivist tradition in research aims for reliability, validity, generalizability, and objectivity (Creswell, 2013). My research sought to ensure trustworthiness in data collection and findings. I recognize that in qualitative research, there is a degree of subjectivity and researcher bias (Hockey, 2006) which I believe is unavoidable as we think, interpret, and write in terms of our own perceptions and values. However, having to listen to the mothers' stories about their lived experiences, I found from an ethical standpoint, that I must attempt in every way possible to present the data in an unbiased manner. Therefore, I tried to represent my participants' stories in the best way I can so that there can be a greater understanding of their world in parenting disabled children in

Trinidad and Tobago. In so doing I endeavoured to upkeep the ethical principles in narrative inquiry as identified in the following section.

3.13 Ethical Considerations

Ethics in qualitative research, by and large, relates to doing good for others and avoiding harm, for example, by maintaining privacy and protecting the rights of participants (Orb, Eisenhauer & Wynaden, 2000). In this study, I was guided by the University of Sheffield's Code of Practice that complies with the British Educational Research Association's ethical guidelines (BERA, 2018). According to these guidelines, research relating to education should adhere to the ethical principles where due respect is paid to data, people, academic freedom, values associated with the research field, and the quality of educational inquiry.

Within the realm of methodologies and procedures in narrative research, Sikes asked us to consider how we will feel if we or our children were to be researched by these procedures; or, if our participants were to read the findings, would they be comfortable with what they find? (Sikes, 2004; 2010). As all research has implications for those involved, I found myself rethinking my position of insider-outsider researcher with regards to ethical issues that could arise because of my position during the research process (Floyd & Arthur, 2012). As an insider researcher and a mother, I considered it a privilege to have the experience of working with these three mothers who allowed me to view intimate parts of their lives involving their children. Although we were of the same heritage, engaging with the participants allowed me further insights into the culture being studied which made me more confident about the research setting (Unluer, 2012). However, in the duality of my role as an insider-outsider researcher, I endeavoured to distance myself from the participants so that I can obtain greater trustworthiness and credibility of data as much as possible. Therefore, my position as an outsider, as someone who does not parent a child with a disability, assisted me in maintaining this balance which also helped to avoid the possible ethical dilemmas that could have arisen from my insider position.

In the discussion of the insider-outsider dichotomy, Dwyer & Buckle (2009) points out that insider-outsider roles are not always clearly defined, as researchers sometimes fall *in-between* the continuum. I found this to be true for as researchers doing

qualitative work, we can never be complete outsiders because of our familiarity with the research topic. Also, we cannot be complete insiders because of our status as a researcher (Dwyer & Buckle, 2009). Thus researchers, according to these authors are always somewhere “in-between” (p.61), never entirely at either end of the continuum. Bearing my position in mind, the way I approached the issue of power relations in my study was an important consideration for me.

3.13.1 The Issue of Power

I was concerned about the power relation in my interviews as there were mothers who were not formally educated and may think I was doing them a favour or that I am considered to be an “important” person. For me, this carried a substantial ethical burden (Sikes, 2010). According to Sikes (2010), the most important consideration in ethics is to “re-present lives respectfully and that we do not use our narrative privilege, or, put another way, our narrative power, to demean, belittle, or to take revenge” (p. 10). In my research, I attempted to mitigate against misrepresentation and maintain integrity (Stutchbury & Fox, 2009; Orb, Eisenhauer & Wynaden, 2000) by following certain procedures. In view of the ethical concerns, I examined the following: assumptions and bias; confidentiality and anonymity; and informed consent and trust, as I believe that the protection of participants in any research study is vital since it has implications about perceptions and children. Christians (2011) suggested that in practicing a code of ethics, there are four guidelines for conducting research which includes informed consent, deception, privacy, confidentiality, and accuracy (in Denzin and Lincoln, 2011, p. 65-66).

3.13.2 Informed Consent, Trust and Deception

Informed consent entails people having the right to be informed about the nature or consequence of experiments in which they are involved (Christians, 2011). In this research I ensured that informed consent was carried out by first, providing “information in advance of the interview and then again at the beginning of the interview” (Patton, 2002, p.407). I also informed participants, that their participation is strictly voluntary and they have the right to withdraw at any time. Additionally, I explained the possible risks and benefits of participating. To ensure that other ethical procedures were followed, I sought ethical clearance from the University of Sheffield to undertake the study. Also, each participant was then asked to sign a consent form before participating in the research.

Clandinin and Connelly (2000) made a point to say that although informed consent is given, “the landscape and the persons with whom we are engaging as participants may be shifting and changing” (p.175) during the research process, and for this, we must be mindful.

The fact that the mothers agreed to be participants told me that they trusted me. I mentioned before the difficulty in sourcing participants for this study. Trust, therefore, was an important factor in this research as these mothers invited me into their homes and lives. My endeavours were to avoid being deceptive in any way (Denzin & Lincoln, 2011; Patton, 2002) during my data collection. After the interviews, I believe that they felt a special bond in sharing their stories with me. From an ethical perspective, I felt compelled to do anything that will not violate this degree of trust the mothers placed in me. One way for me to do so was by maintaining strict confidentiality.

3.13.3 Privacy and Confidentiality

In conducting this narrative research, codes of ethics demand that there is a need to protect people’s identities by being confidential and maintaining anonymity (Christians in Denzin & Lincoln, 2011; Patton, 2012). To do so, I explained to the mothers that confidentiality can occur up to a certain point in the research process, in that the findings may be shared with a wider audience. Sikes (2010) notes that in writing about people “confidentiality and protection of identity” (p.10) is important. She said that “pseudonyms and other attempts to disguise can only really work in the wider world where readers don’t personally know or know of, the people concerned” (Sikes, 2010, p.10). To protect my participants, pseudonyms were used for both the mothers and their children. Also, their location was generalized to a broad location and not necessarily where the mothers lived. I had to bear in mind, Trinidad is a relatively small island, and as Sikes said “anyone who is an insider, however, will be able to work out who is who” (Sikes, 2010, p.10).

3.13.4 Accuracy and Bias

Representing participants falsely is unethical. Ensuring the accuracy of all the data collected from the participants was crucial to my study (Christians in Denzin & Lincoln, 2011). I was dealing with a vulnerable population of mothers from different income

backgrounds who parent disabled children. Two mothers were single parents. Their stories, secrets shared, and their lifestyles were highly confidential. I took care in my findings not to misrepresent them because I felt I had a moral obligation to represent my participants as honestly as I can (Christians, 2011). I rechecked my transcripts with the recording and double-checked my findings to ensure that I did not draw false conclusions. I had to be mindful of my own biases and ideas about mothers who parent disabled children in analysing the data. In many instances, the conclusions drawn were very different from what I imagined prior to the research. In this way, I guard against my own bias and assumptions I held about disability and about mothers who parent disabled children.

In qualitative inquiry, the researcher is involved in interpreting and attributing meaning to the stories told by my participants. Since, I believe that interpretation is subjective and therefore, cannot be bias-free, (Clandinin & Connelly, 2000) I recognized that my own biases and value judgement may find their way into the research process. Therefore, throughout the process, I had to constantly refine my judgements so that I do not misrepresent my participants.

3.14 Chapter Summary

In this chapter, I have presented the methodology I used for this research. I have looked at the research questions in relation to the methods and procedures, research design and justification for the approach, assumptions, and bias, my role as researcher, participant's selection, limitations of the study, the data analysis plan, trustworthiness of data, and ethical concerns. In the following chapter, I will present a detailed description of the findings and analysis using the procedures employed. I hope that my appraisal of the contributions from different authors will explain why I was particularly interested in storytelling belonging to the post-positivist paradigm specifically to the narrative approach to inquiry. Narratives have been with us since time immemorial and have depicted the experiences of human beings (Webster & Mertova, 2007). Through narratives, our voices reverberate those of others in the social world by listening, recording, telling, and retelling the stories that they tell us. How we interpret them as researchers depend on our own social upbringing, our worldviews (Creswell, 2009;

Patton, 2012), and the construction or reconstruction of our reality. How we present data as rigorous and trustworthy (Mishler, 1990) is dependent on our own ethical stance in representing our participants as we ponder “carefully about the consequences of being involved in research that adopts particular methodologies and procedures” (Sikes, 2004, p. 26).

4 Chapter 4 - Findings, Analysis and Discussion

4.1 Introduction

The purpose of this chapter is to present the findings and analysis of a qualitative narrative study on mothers of children with a disability living in Trinidad and Tobago. This chapter gives eminence to the voices of three mothers' lived experiences in caring for and educating their disabled children in Trinidad and Tobago. In the previous chapter, I mentioned that I examined the data using Clarke and Braun's (2014) Thematic Analysis and Pope et al. (2000) Framework of Analysis. I also described the process of reviewing the raw data before I coded and categorised it to generate themes. I present these themes to illustrate my interpretation of the findings, and I then discuss them in relation to the research questions and learnings gleaned from the literature review in Chapter Two.

This study's aim was to explore the lived experiences of mothers of disabled children, including the internal meaning they derived from raising their disabled children. Therefore, the study was designed to contribute to the limited research on mothering a disabled child in Trinidad and Tobago. Mothers were requested to engage in in-depth interviews about their thoughts, experiences, and feelings. The intention of the research was to focus attention on the primary caregivers of disabled children, in this instance, the biological mother, by gaining access to their views on caring for a disabled child that they birthed or "created". Thus, an objective was to add to the more psychologically centred disability literature on the maternal caregivers' experiences of disabled children in Trinidad and Tobago. As mothers related their experiences of schooling and support, another focus was to explore their perceptions about the government's role in providing educational and other social support services for disabled children. From an ethical viewpoint on disability, I sought to provide an avenue to give voice and autonomy to those in the realm of disability who are closest to their disabled children (Green, 2007; Lalvani, 2011; Landsman, 2005).

The presentation of data is analysed according to the themes that emerged from the data findings and in relation to the research questions. There is a total of three themes that emerged from the data which broadly encapsulate the psychological process on mothers' caregiving experiences, maternal responsibility, and support services for mothers of disabled children. Each theme is followed by a critical discussion and analysis

of the data. In this chapter, I addressed the research questions through the themes identified. The verbatim representation of the mothers will suggest the answer to the first research question which I called the “what” question of this thesis and which inquired into the value of the mothers’ personal and social experiences. The other discussions will address the other research questions which sought to inquire into the perceptions of the mothers of both their role as caregiver as well as the governments’ role. The implications of these experiences and perceptions will be considered in the last chapter where I will address the fourth research question that focuses on the lessons learned from this investigation.

In addressing research question one, the lived experiences of mothers who parent disabled children can be described as unique because of the deeply personal and psychological processes mothers undergo in all areas of their disability journey. According to Zulfia & Allenidekania (2020), disabled children develop differently from typical children and therefore “need special attention in optimizing their development” (p. 8). Thus, as mothers are the main caregivers of their children (Al Sayed, Alaskar, & Alonazi, 2020; Collins & Coughlan, 2016; Landsman, 2005;) it can be said that the burden of care resides with them, and as a result, mothers are more likely to undergo mental health problems regarding caring for and educating their disabled children compared to mothers of non-disabled children (Zulfia & Allenidekania, 2020).

In this section, I will present the findings and discuss the ways mothers’ experiences are unique in the areas of diagnosis, unpreparedness, and finding happiness in their caregiving experience. Although mothers’ experiences entail a life span journey in caring for their disabled children, the findings reveal that experiences in these areas are different from typical mothers having babies that do not need a particular diagnosis since their children are born “normal” or without impairments (Landsman, 2005; McDougall, 2017). In proceeding, I will discuss how mothers’ experiences can be relevant to understanding disability in the literature. As mentioned in Chapter Three, the participants’ names are Ana, Prabha, and Sherma and their children are Kris, Kate, and Val, respectively.

4.2 Theme 1: Unpreparedness

Unpreparedness emerged as a theme in this research and I use it to describe an amalgam of the following events: dealing with the advent of diagnosis, the notion of mothers' expectation versus reality, and the idea of having a "normal" child while creating happy moments between mother and child. Hence, unpreparedness constitutes part of the unique set of circumstances experienced by these three mothers in having a child with a disability.

The findings indicate that preparedness in the mothers' ongoing journey before and after diagnosis and their expectations of their disabled children was an area deserving of examination as it affected the psychological wellbeing of these three mothers (Collins & Coughlan, 2016; Landsman, 2005). In this study, it was conclusive from the mothers' stories that they were not prepared for the reception of a child with a disability, which means that their expectations of having a normal child will not be met. Ana explained:

"Well, nothing prepares you for having a child with a disability, nothing, absolutely nothing. People take for granted that, they will have a "normal" child, a child that progresses, mentally, physically, normal. When you are given this news that your child has delayed development, due to an illness, for us, our focus was on his illness. Every resource we had went to finding an answer, to finding somebody to help him get over this illness... it was very, very demoralizing."

Sherma also expressed her level of distress in receiving the diagnosis of her daughter, Val, and the ensuing struggle: *"But I know, being a parent with a child like that, it is, it is difficult to accept and to live with. I have two other children and they [are] normal, one before Val and one after."* Prabha articulated her feelings about not expecting a child with a disability and the difficulty in parenting her daughter: *"it's really hard to put up with disability. When I found out she had a problem, I couldn't eat, I couldn't sleep, I couldn't do anything, I felt so sorry for her, I used to cry, day and night."* It is evident that the support mechanisms for parents receiving a diagnosis were not present. They experienced trauma at diagnosis (Emerson, 2020) and mothers were left alone to find a way to cope in a seemingly disabling environment with the lack of services and professional and medical advice.

The findings also showed that preparedness is related to diagnosis and the idea of normalcy. A mother having a child with a disability begins her unexpected journey (Collins & Coughlan, 2016) when the child is diagnosed with a long-term illness or an impairment that results in the child becoming disabled. For all three mothers I interviewed, the diagnosis of their children's disability was a significant life event. One of the three mothers received the diagnosis from the healthcare professional at the child's birth; another mother learned of the diagnosis soon after the birth of her child in a follow-up doctor visit, while the third mother received the news when the child had reached the age of six. Regardless of when the diagnosis was delivered, I pinpointed two observations: (1) there is very little, if anything, that prepared these mothers for the unexpected journey of raising a disabled child in Trinidad and Tobago; and (2) mothers had to adjust their thinking and lifestyle before they could fully accept their children's "abnormal" diagnosis (Russel, 2003).

The findings indicated that at the time of diagnosis, all participants had difficult times in accepting that their children were not "normal". On a personal and psychological level, each mother confronted this news of her child having a disability as something sorrowful and exhibited fear and anxiety of not knowing what to do. Ana explained the frustration of diagnosis:

"Our challenges started very, very early. He was diagnosed with his illness when he was less than a year old. Nobody could tell us what was wrong with him, nobody could tell us what's causing his seizures, there were doctors who told me to try medications, and to try another."

Prabha also expressed her sentiments:

"Well, when she [was] born she was active, playing...everything, but I don't know, when we carry she [her] to the Doctor, the Doctor said she couldn't hear, she couldn't talk, and when the child [was] born they tell [told] me I had German Measles. In 1983, all the children who[were] born like this, the [their] parents had the German Measles."

In alluding to the idea of being normal, however, Sherma, expressed her view:

"Well from the time she was born, we didn't know, she was a small child but nothing [was] wrong to her. But we did take her to a specialist and they still didn't say. They said she had delayed development"

Like Sherma, Prabha justified that she gave birth to a perfect child who just happened to have an impairment that disabled her. Prabha, in referring to her daughter, said *"she's normal, it's just she don't [doesn't] hear and don't [doesn't] talk [speak], that's the only*

problem". Ana pointed out that her goal for her son regarding his disability was "to get him to the point where it's not noticeable". In other words, her goal was to assist in his development where he would appear "normal" in society. Sherma also remarked: "when I look around, and see children with disability, I will say, thank you, Jesus, my child could still see about [take care of] herself and do some things like normal children, you know".

Sherma was happy her child's physical appearance was normal and her disability was not visibly obvious. Again, this idea mirrors the perception that an impairment of the body that is clearly and immediately visible places the child at a greater disadvantage than others who are not visibly disabled (McDougall, 2017), alluding to the medical model of disability with its accompanying stigma. Normal for each of these mothers was redefined in their own terms. Ana said, "the thing is because he is my only child, he is my normal, I don't know anything different." Prabha indicated that her daughter is normal, and stated: "if I don't tell people she can't hear or don't talk, they won't know." Sherma also indicated her view of normal. In speaking of her daughter, who is a full adult but developmentally delayed said: "She went to the normal school, and she didn't excel but, she is a normal child". In providing an example Sherma further relates: "Like she knows when her period [menstruation] is coming, she ticks off her date, but she lets me know like a five-year-old; she will let me know".

The mothers' learning of the impairment or disability diagnosis of their children brings to mind Landsman's (2005) idea that all mothers *expect* to have perfect babies or rather, people expect mothers to make perfect babies. When this is not a reality for mothers, it means the start of a journey that is daunting. They have to go through the process of acceptance of their new "norm". As Prabha explained, "when I find out she had a problem I couldn't eat, I couldn't sleep, I couldn't do anything...It is really, really difficult to see about." Sherma also said: "being a parent with a child like that, it is hard, to accept and to live with". Ana also added: "for me, living with a child with a disability has brought into focus for me that not everyone knows how to deal with someone with a disability."

Apart from the sacrifices made for their children, or the trauma they faced at diagnosis and throughout their disability journey, the findings also showed that the mothers found time to reflect on the happy moments and the "unexpected blessings" of

their parenting journey. In relating their happiness and talking about the moments that bring joy to them, Ana explained:

“His progression, was like the first two sentences and then like two paragraphs. He is so sweet, he is so kind, he is so loving, he shows other children how to play, how to share, how to be nice, how to say thank you, and I feel proud. I hope he gets that from me. People look at him and they see imperfect, and I look at him and I see a blessing.”

Prabha also expressed pride in her daughter: *“the principal still has all the pictures with my daughter. One of the doctors want she [her] to come and teach them sign language. The nurse, and all of them went crazy over this child.”*

Sherma in her unique way expressed her pride by talking about the lessons she learned from her daughter:

“I have learnt so much from her, everyday things, what happens every day, and what we should do, and what we shouldn’t do and I feel very good when I listen to her to be honest, because she talks about everything, and she was well disciplined. Val is a loving child. I know she is a slow learner, but she is not a miserable child you know. Caring for my child has taught me patience, understanding, plenty things, most of all is patience, and I have that. It has [There are] children who are worse off than mine, so that is what gives me courage to be with Val. That is what I live for.”

4.3 Discussion on Unpreparedness

Being unprepared for the birth of a child is a rare occurrence. Under usual circumstances, where, for example, if a mother is not a rape victim or forced to give birth, most mothers look forward to and plan for birthing a new baby. Where the circumstance turns unique is when they are unprepared for the birth of their children which is what happens when a child is born with an impairment or long-term illness that causes a disability (Landsman, 2005). All the mothers in this study expressed their unpreparedness for their children at diagnosis and in the later stage in their children’s development. In fact, throughout their children’s lives, these mothers had to be in a constant state of preparation. This is because they would have had certain expectations about giving birth or about their children’s development milestones (Russel, 2003). However, as expectations were not being met while their children were growing, meant that these mothers constantly had to be prepared for the unfamiliar. As mentioned in Chapter Two, they, therefore, had to “review” their unfulfilled expectations and modify them in light of the new experiences (Russel, 2003, p.145).

The mothers in this study could not determine what the future of their children would bring since the trajectory of disability development was unfamiliar to them (Runswick-Cole & Ryan, 2019). By not having previous experience in caring for children with impairments or being disabled they were unprepared for their disabled children and as a result did not know what to expect (Russel, 2003). For each of the two mothers, Ana and Prabha, their first and only child had an impairment and was disabled. Prabha confided that she had aborted her second pregnancy. I believe her decision to abort was as a result of her belief that she could be the cause of her child's disability, or it could be because of the hardships she encountered in caring for her first child, the adjustment in expectations she envisaged, or her unpreparedness to undergo the possibility of having another child with a disability. Ana had a similar encounter regarding losing a baby, although her reasons may have been different. She did mention that she had a miscarriage and she was satisfied with not having another child, although she did want it at one point. However, because of the demands of her first son, she decided that she wanted no more children.

Sherma's first child was born without a disability and her second child was diagnosed with a disability. Therefore, her state of unpreparedness would probably have been greater. In Sherma's case, having produced a "normal" child before, there was an expectation for another similar experience at or post-birth. However, she discovered that the child had a delayed development from a cognitive disability at age six. Her level of expectation for the development trajectory for her child was probably shattered and difficult to handle (Tsai, Tsai & Shyu, 2008). It meant that she had to adjust her expectations to be prepared to raise a seemingly abnormal child with a disability. In an unfamiliar journey with their children, the mothers in this study had to rethink what they expected for their children and adjust how they will manoeuvre their lives to fit their children's needs. According to Russel (2003) reviewing one's expectations "is an essential process in developing a person's understanding of any new situation" (p.144).

Having expectations are a normal occurrence for any parent regardless of whether or not a child is disabled. A parent may expect that their child or children will talk, walk, play, go to school, work, get married have children, and so on. Ana, for example, hoped her child would work someday. Prabha expected her child to find a job but faced the

stigma of unemployment of the disabled in Trinidad and Tobago (Seetahal & Charran, 2018). What made these mothers' experiences unique, I believe, is that they have had to learn how to *not expect*. This they did by being constantly in a state of preparedness for what next may happen with their children. Internally, they have had to change their expectations to their newfound reality. Externally, they also had to deal with the stigma from outsiders as other people, particularly family members may also have had expectations of these mothers and their children.

Being "unprepared" is not a normal circumstance for parenting children and adjustments to being prepared for a child with a disability can have a profound effect on the psyche of a mother. How could you not expect anything from your children? That is a question I asked myself as a mother because I also have expectations of my own children. There could also be the notion that these mothers had to change their expectations from having children without a disability to having children with a disability, as in the case of Sherma. This called for a mental adjustment that brings with it different levels of stress (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016). Additionally, without guidance and support, this situation can be a very daunting experience for mothers of disabled children (Al-Kandari & Al-Qashan, 2010). Their uniqueness in parenting children with impairments or disabilities is something that I believe should be understood on a wider scale. The certainty of development mothers may once have imagined before birth or diagnosis was not guaranteed. These mothers expressed doubts and fears about what will happen to their children, how will they take care of themselves if they (the mothers) should die and they worry about their children's future survival. Such feelings represent some of the mental adjustment and stresses associated with being unprepared in raising disabled children and simultaneously having to "re-prepare" for their onward caregiving journey.

With reference to preparedness and diagnosis, mothers parenting disabled children endure an exceptional set of experiences as do their children (Harvey and Long, 2020; Lalvani 2011). In her 2009 book entitled *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*, Gail Landsman wrote extensively about diagnosis and the traumatic effect it has on mothers who care for disabled children upon receiving the news from medical professionals. As mentioned in Chapter Two, interacting with doctors at the stage of diagnosis had implications for these mothers and how they

prepared themselves for raising their child who has a disability (Graungaard & Skov, 2006).

Medical diagnosis according to Graungaard and Skov (2006) can mean that parents subconsciously expect doctors to give them an assurance of the future development of their children. In this regard, when a medical expert gives a diagnosis of a child's disability, their words will carry some degree of permanence (Landsman, 2009). This permanence is what the mothers in this study described as difficult, especially not knowing, according to Ana, "*where to turn*" for advice and assistance. Hence the diagnostic process influenced the way the mothers coped with their new life with their disabled children. However, for the mothers in this study, the mental, physical, psychological, or emotional preparation for such news was not present before or after diagnosis (Boström, Broberg & Hwang, 2009; Singh & Chopra, 2020). Ana explained how "*nothing*" prepares a mother for such news and she also refers to the presumption that people take for granted that all mothers will produce "normal" children who will "progress" as per conventional developmental milestones. Emerson (2020) also confirmed that mothers go through psychological trauma after diagnosis. They need assistance in navigating the world of disability so that they can build resilience to ensure their children's survival and development. I concur with Smith, Cheater, and Bekker (2013) that the mothers in this study experienced chronic sorrow and enduring grief for their children upon diagnosis. Prabha shared the pain she felt and the sadness knowing that her daughter was profoundly deaf and unable to speak. The mothers in this research, therefore, had to undergo a period of "parental adjustment" (Carlson & Miller, 2017) upon receiving the diagnosis of their disabled children. Undergoing this emotional trauma, had to some extent a negative impact on their psychological ability to care optimally for their disabled children.

At diagnosis, it was a difficult realization for the mothers to accept and adjust to *creating* an imperfect child (Landsman, 2009). All the participants in this research endured, on a personal level, feelings of blame, guilt, sorrow, and grief even, before acceptance of their children's disability. In this regard, Cole and Ryan (2019) note that mothers are usually subjected to being blamed and held responsible for the poor genetic inheritance of the impaired bodies and minds of their disabled children. The sorrow the mothers felt could emanate from what Barbosa, Chaud, and Gomes (2008) referred to as

the death of the imagined, ideal, or desired child. These authors also said that mothers may be required to first experience the grief process of the desired or lost child before accepting the “real child” (p. 47). Acceptance was difficult and sometimes the mothers needed to have an explanation for their children’s disability which can allude to the medicalized perspective of disability (Landsman, 2009). For example, Prabha explained that she had German Measles (or Rubella) as a means of justifying why her child was born with a hearing impairment. She generalized also to say that all children who were born in the same year as her daughter with hearing and speech impairments came as a consequence of German Measles. This is an important observation since, unlike mothers who do not parent disabled children, it points to the exorbitant degree of psychological stress a mother can feel upon hearing the news of her child’s condition and not knowing where or to whom to turn to for help (Yousafzai, Farrukh & Khan, 2011; Green, 2005). From listening to their stories, the mothers not only projected the loss of dreams for their children but also the loss of dreams for themselves (Brown, 2013). Therefore, their mental adjustment to life was insurmountable at the point of diagnosis.

From the stories mothers told, and from my own experience in working in the health sector for eight years, I do know that there are scarce resources and services available to enable mothers of disabled children to prepare for diagnosis and beyond in Trinidad and Tobago (ECLAC, 2018; Charran, 2018). It may also be that the mothers were not aware of all the services available, public or private, which they can access. Additionally, as Ana’s experiences showed, and as Landsman (2009) indicated, medical advice may be available, although not always accurate or sensitive to mothers’ feelings. In all three cases from the mothers’ accounts, after diagnosis, mothers were left to fend on their own with little or no medical advice or follow-up support on how to manage their children. Hence they were left with very limited knowledge and preparation for their unexpected journey. Regardless of the lack of preparedness, these three mothers had little alternative but to continue with their journey and heavy care burden to raise their disabled children.

From a psychological perspective, feelings of stress, fear, or trauma experienced by mothers constantly can be transferred to children (Sinason, 2002). As I mentioned in Chapter Two, there are times mothers may feel abjection and ambivalence towards their children (Harvey and Long, 2018). In the findings, Prabha described an incident where

her recourse to action was becoming violent towards a neighbour who verbally tormented her about her daughter's disability. Her feelings of anger and frustration about the situation resulted in Prabha physically fighting to protect her and her daughter's reputation. Psychologically, as Harvey and Long (2018) explored in examining the ambivalent feeling of mothers of disabled children, Prabha may display these feelings of anger because of the inability to control the permanence of her daughter's disability or the labelling and stigmatization faced from 'others'. It was an almost admirable quality nevertheless that such anger was directed towards "others" and not towards the child herself. Sherma also shared her experience about the anger she felt towards her daughter, she said that *"sometimes she gets angry with me...I went to a psychologist for her behaviour. I used to get angry. I can get angry and leave her and go, but I don't do it. I had to 'cool'[calm] myself just for her."* Sherma had to find ways to subdue her anger so as not to hurt her daughter in any way.

In some cases, this frustration or abjection can be directed toward the child who is disabled. An example can be drawn from an incident twenty-eight years ago in Saskatchewan, Canada. In 1993, a 40-year-old father, Robert Latimer, placed his 12-year-old daughter, Tracy, who had a severe case of cerebral palsy, in his vehicle, ran a hose from the tailpipe to the inside of the vehicle, and turned on the motor. Tracy died from inhaling carbon monoxide exhaust fumes. This act of filicide is an example of the more extreme type of actions, as discussed in the literature, that Harvey and Long (2018) referred to as the abject, the dichotomous feeling of hate and love not unfamiliar to parents or caretakers of disabled children. The father, Robert Latimer, wanted to end what he saw as the suffering of his child and viewed it as a mercy killing. He was eventually charged with second-degree murder (Farnsworth, 1994). This story unearths the importance of understanding the experiences of the mothers in this study since they are the main caregiver. It serves to highlight the frustration, and distress caregivers may experience which in most extreme cases can result in disability filicide. However, it is my view that such extremity cannot justify murdering a disabled child, or any child for that matter, and can still be considered as the selfish side of caregiving.

Despite living through the unpreparedness of having a child with a disability in Trinidad and Tobago, the mothers in this study did express the joy and happiness they experienced in caring for their children. However, I feel obligated to express my thoughts

here. I must admit that in doing this thesis, I had to confront my own biases in my writing. In the beginning, I thought only about the stress and hardship associated with parenting a child with a disability. My thinking is consistent with the literature which indicates that there is insufficient focus on the positive aspects of raising disabled children (Pillay, Girdler, Collins & Leonard, 2012; Green, 2007). In my initial review, I only examined the difficulties of the mothers' experiences, ignoring the positives that I learned from the mothers I interviewed. I think this is because growing up in Trinidad and Tobago, I had been conditioned to think of disability only as a stressful occurrence, a taboo. I refer here to the example I gave in Chapter Three about my cousin, Anita, who was disabled and whose mother was stigmatized and socially isolated. Admittedly, I was therefore a little surprised to find out that the mothers in this study, possibly like many other mothers, expressed real joys and contentment in being with their children (Lee 2013; Zulfia & Allenidekania, 2020). I, therefore, had to confront my own stigmatizing beliefs about disability and reconstruct my own reality based on my experiences with the participants (Burr, 2003; Galbin, 2014).

The findings revealed that the mothers took comfort and pride in their efforts, knowing that they were the ones responsible for the achievements of their children's development. While in some societies, parents of disabled children may view having a child with a disability as a curse or a misfortune (Munyi, 2012), the mothers in this study spoke about their experiences as a blessing. It was as if they had a forum to voice their feelings, their pride, and their joy of parenting in my presence to reassure me that they did a good job at mothering. Ana expressed that she hoped her son's open display of love and kindness to his classmates was a trait inherited from her; she said "*I feel proud. I hope he gets that from me.*" Sherma, in speaking about her daughter also noted, "*she is [a] little bit slow with her speech and a little tardy, but, I manage all of that, because I give myself courage as a parent. It was more difficult for me but I manage, and I think I did a good job.*" Prabha also expressed her feelings: "*I am very proud of my daughter, really proud, although my daughter can't hear and she can't talk, I [am] real proud of my daughter.*" These verbatims support the literature, suggesting that mothers need recognition for their parenting roles (Woodgate et al., 2015) as it encourages them to continue caring. Social support has manifestly been found to have a positive effect on mothers' caregiving roles (Junaidi & Dewantoro, 2020; Ferguson, 2002).

One of the positive qualities I found common to all the mothers in this study was their resilience which in the long term served as a coping strategy (Savari, Naseri, & Savari, 2021; Alsharaydeh, Alqudah, Lai Tong Lee & Wai-Chi Chan, 2019). Heiman (2002) defined resilience as “the ability to withstand and rebound from crisis and distress” (p 159). One of the mothers, Ana, spoke about the stigma of religious beliefs and the impact it had upon her. She was “cursed” by a close family member for doing “bad deeds” in her life and was therefore punished by having a child with a disability. In the interview, this was a very emotional and difficult recollection for Ana and for me as well in handling her reaction. Ana was of the same faith as her abuser, who was of the Hindu faith that subscribes to the concept of Karma, the idea that one is punished or rewarded based on one’s past actions (Kamenopoulou & Dukpa, 2018; Gupta, 2011). Ana remained in the faith despite the “curses” hurled at her and was resilient in the way she coped with the stigmatizing attitude from the offender. In my view, such optimism and positivity are forces that can provide motivation and insights into parenting for all mothers of disabled children who must cope with cultural adversities regarding their caregiving.

In this section as I focused on research question one, I examined the findings of the data by looking at the mothers’ experiences regarding unpreparedness, diagnosis, expectations, and happiness in their caregiving experiences while raising their disabled children in Trinidad and Tobago. The data showed that mothers underwent a unique set of experiences that differed from typical mothers who do not parent disabled children (Al Sayed, Alaskar & Alonazi, 2020). They encountered various problems at the diagnostic stage of their children, whether at birth or later in life. Their experiences entailed a lack of guidance and preparedness in how to manage their children. According to the literature, such uncertainty experienced by mothers have a negative psychological impact on the general health and wellbeing of mothers (Li, Lam, Chung & Leung, 2019) leading from the state of feeling ambivalence to abjection (Harvey & Long, 2018). These feelings can, therefore, impact the quality of care mothers deliver to their disabled children (Al Sayed, Alaskar, & Alonazi, 2020). However, the data also revealed that despite the negatives of diagnosis, or stigmatized beliefs, mothers still find happiness in their journey (Junaidi & Dewantoro, 2020; Al Sayed, Alaskar & Alonazi, 2020) following eventual acceptance of their disabled children. The mothers also develop courage and resilience in the face of adversities stemming from cultural traditions.

As I conclude this section, one of the notable findings is that the uniqueness of mother experiences is characterized by the intense psychological processes they undergo in having disabled children. Their unpreparedness for their journey before and after diagnosis meant a mental adjustment throughout their lives. They have had to learn how to change their expectations of their children, for example, how they saw their children being schooled or acquiring survival skills. Additionally, they have had to deal with not having a “normal” child and how to provide for the enjoyment and appreciation for the small developments and positive outcomes of their children. The value of understanding these experiences can indicate to mothers themselves how they need to adjust their thinking in light of the values held by members of society (Russel, 2003). Additionally, increased understanding of mothers’ lives can indicate to policymakers, the type of interventions that may be applicable so that mothers can be given better support and an enhanced quality of life for themselves and their children.

4.4 Theme 2 - Maternal Responsibility

Maternal responsibility is a theme that encapsulates several aspects of the mothers’ stories derived from the data. In this section, I will first examine the findings and discuss mothers’ changing perceptions of disability. Second, I will explore mothers’ perception of their roles by examining the concepts of ownership, self-efficacy, and the nature of the disability, and their perception of the cause of their children’s disability. As this theme has several components, I will present the findings for each, immediately followed by a detailed discussion on the concepts.

4.4.1 Changing Perceptions of Disability

As I address research question two in this section, I will first present a discussion on the way mothers perceived disability. The mothers in this study were not asked to specifically define disability or describe what it meant to them. However, from the conversations about their unique experiences, their perspective naturally emerged which gave credence to their perceptions surrounding disability. I felt it was important to understand this aspect of the mothers’ experiences as it can inform how they see their roles as well as those of the government. I concur with Harvey (2018) that many times, non-disabled researchers are the ones who write about disability research and that researchers should include the actual words of those who experience disability as their

voice must be heard. Hence, in this analysis, I will use the verbatim as text in some instances as part of the literature to contextualize the mothers' stories.

In assessing her understanding of her son's disability Ana explained that:

“He was born with this illness which caused his disability and he is an only child who happens to be disabled, and that's what we know. Society, especially in Trinidad, it's such that people with disabilities, physical and even more so mental disabilities, are treated differently, they're left out, they're shunned, they're not included in activities, like you know, a good education and sports”

Sherma indicated that her daughter *“went to the normal school, and she didn't excel, she had delayed development. That is all they said to me, I just feel sorry for her, like, and as I tell you it does bother me, I don't like to talk about it when she is there.”* Prabha also specified her views in speaking about her daughter who is a deaf/mute *“children with disability, if you look at them, you will really cry. you will feel sorry for [those] children. I used to cry, day and night I used to really, really cry.”* She also referred to an incident that she recounted where she maintained feelings of sorrow and sympathy: *“Sunday I went to a Thanksgiving and it had [there was] this little baby and she had [about] a year. She couldn't hear, she couldn't talk and it was really sad and touching when I see this little baby. She reminds me of my daughter”.*

4.4.2 Discussion On Changing Perceptions of Disability

In Chapter Two, I introduced the charity/religious/moral model of disability that existed since biblical times (Bennett & Volpe, 2018) which, in my opinion, served as a basis upon which more recent models of disability evolved. I also drew reference to how this model progressed towards society's creation and acceptance of the medical model of disability as the field of medicine advanced (Retief & Letšosa, 2018). With reference to Trinidad and Tobago, the beliefs of both the charity and medical models are still held by people in society. The entrenchment of the medical model in the minds of people is difficult to erase as medical practitioners also subscribe to the tenets of this model of disability (Ryan, 2005; Oliver, 2013). Additionally, parents who have disabled children depend on health experts for the diagnosis and advice of their children.

The medical model locates impairment of the body and minds within the individual and thus regards disability and impairment as similar (Bennett & Volpe, 2018;

Oliver, 1990a, 2013b). Considering this, the mothers in this study who never parented a child with a disability would possibly once have internalized the medical model which would have coloured their perceptions by its stigmatizing beliefs about disability (Landsman, 2005; Bennett & Volpe, 2018). Therefore, the mothers would have had preconceived medicalized notions about having a child with a disability (Donoghue, 2003). All three mothers in this research, therefore, had to deliver their parenting role amidst strong social discourse that devalues and dehumanizes disabled adults and as a result can harbour low expectations for being successful parents for their disabled children (Green, 2007). However, the mothers' perception and understanding of disability would probably have changed when they actually conceived a disabled child. They would have had to reconstruct their reality about disability as their personal and social experiences would have taken on a different dimension from the assumptions they once held (Galbin, 2014).

The way mothers understood disability can indicate the model they embraced, despite not formally knowing about models of disability. Here I will present mothers' verbatim that indicated their beliefs about disability as well as the model to which they subscribed based on their lived experiences. The importance of this is that it can have implications for how they respond to the needs of both themselves and their disabled children (Smith & Bundon, 2018; WHO, 2011; Madi et al., 2019). The data showed that Ana's views on disability were more coherently aligned to both the social and bio-psycho-social model of disability discussed in Chapter Two. In her explanation, she distinguished illness from disability, clearly showing an allusion to the aspect of functioning that The International Classification of Functioning, Disability, and Health, (WHO, 2011) spelled out in its description of the bio-psycho-social model. She explained that "*for me, someone with a disability, is someone who cannot function within the normal parameters of society, or that society has laid out.*" Ana's perception about disability was also aligned to tenets of the social model of disability as she differentiates illness from disability. It must be noted that the bio-psycho-social model includes principles of the social model of disability. Hence Ana's view included aspects of both these models. In speaking about her son, Ana stated that "*his illness is separate from his developmental delays, his illness caused his developmental delays.*"

It was clear to me that Ana did her research about her child's condition and his disability, and unlike the other two mothers in the study, she saw the medicalized view as different from the social functioning aspect of disability (Oliver, 2013). Ana held a strong view that the inability of her son to function optimally was clearly something that society could address. As the social model and the bio-psycho-social model of disability suggested, society contributes to a large extent in disabling individuals and therefore it is society itself that can remove the barriers to inclusion and functioning (Oliver, 2013; WHO, 2011). Hence Ana felt that her son would be more equipped with the necessary skills to cope in life if more structural and societal barriers were removed.

In referring to the literature where Qiong (2017) spoke about perception and how it concretizes over time, I found Prabha's views relate to the charity model of disability. This model takes a view that disabled persons must be pitied and as a result should be cared for by others (Retief & Letsosa, 2018). From Prabha's verbatim, her expression of sorrow was very strong. She reminisced about her daughter when she expressed sorrow for the baby she saw at a thanksgiving function who was both hearing and speech impaired. In the interview itself, she was emotional and resented the way society treated her daughter. The sorrow the mothers felt for their children indicated to me that they still held notions of pity for disabled persons and particularly their own children. Ana for example, in speaking about accessing educational services for her son indicated that *"maybe if somebody saw his face, you know they would not be able to say no to him cause he's such a sweet child and has such an engaging personality"*. Therefore, the mothers' perception of disability is one that relates to the charity model as well as the social model as they all felt more could be done by society to address the needs of the disabled children.

The mothers' verbatim, to me, indicates that before having a child with a disability, these mothers held certain notions and perceptions about disability that stayed with them (Madi et al., 2019). The sorrow they felt for disabled children in itself stigmatizes identity (Goffman, 1963). I also believe that perhaps the mothers' experiences prior to giving birth to disabled children could be pre-determined based on their views about disability. For example, this notion of pitying disabled persons can indicate shame the mothers will feel to have a child with a disability (Hassan, Hamid & Eltayeb, 2021). Such feelings can result in depression and self-isolation (Green, 2003). Therefore, having these thoughts when their children were born or diagnosed with a

disability would also mean that they could isolate and exclude them from the public's eyes (Li, Lam, Chung & Leung 2019; Green, 2003; Junaidi & Dewantoro, 2020; Goodley & Tregakis, 2006).

Thus, having a child with a disability affected how the mothers responded to the notion of disability, how they may have accessed services or support from others, how they thought about what other people may think about them, and how they viewed themselves in their caregiving roles (Raff, Mire, Frankel, McQuillin, Loveland, Daire, Grebe & Rosenbrock, 2021). However, I think that whatever the preconceived notions of disability were before having a child with a disability, the mothers' perceptions are likely to have changed upon giving birth or becoming aware of their child's disability. They would have had to adopt a different lens for understanding their caregiving roles and the meaning of the disability experience, much like what the social constructivist theory purports (Galbin, 2014) where an individual's realities and truths are reconstructed based on their interactions and experiences.

Therefore, understanding mothers' perceptions can provide insights into how their perceptions changed over time by having to raise disabled children. Whereas they may have once held the view that disability is to be treated from a charitable perspective, the findings showed that their views changed to the more social or bio-psycho-social model of disability discussed in Chapter Two. I, therefore, contend that understanding their perceptions and experiences, can also signal to society that if we know what it is like to live with disabled children, our perceptions may also change, so why not do it now. As the literature indicated, ninety-nine percent of the Trinidad and Tobago population do not parent disabled children. Despite that, however, disability should not be viewed strictly from a charitable perspective. Understanding these three mothers' stories can indicate to society what is needed on the broader scale to assist disabled children and to curb the stigmatizing beliefs that currently exist. Therefore, a change in perception can reflect a change in understanding that may improve the way society responds to disability and the way it supports mothers of the one percent of the vulnerable population in Trinidad and Tobago.

In this section, I continue to address research question two which examines the way mothers perceive their caregiving roles. I will discuss the notion of ownership and its relation to the protection mothers feel towards their children as well as the concept of death or dying.

In Chapter Two, I presented the notion of ownership argued by Jeske (1996) where mothers may take the view that their disabled children are their “property” because of the mothers’ ability to procreate by virtue of their labour (Jeske, 1996). The findings in this study revealed that the mothers assumed ‘intense parenting’ roles (Woodgate et al., 2015) which can be a consequence of the notion of ownership purported by Jeske. For instance, Prabha tells: *“I never left that child with anybody, even in school. When we go to school, I used to stay all day.”* She later added, *“I don’t know about anybody else, but I could talk for my daughter I real [really] catch my tail [struggled], to mind [take care of] my daughter to make she [her] what she is right now”*. Speaking about her son’s loving behaviour towards his teacher and classmates at school, Ana noted: *“I feel proud that he gets that from me, I hope he gets that from me”*, she says with a smile. She further explained *“but when I am here, it’s me and him, and I will like to think that I have had some impact on how behaves, how he treats people, because he is my child.”* Ana also spoke of her in-laws and emotionally revealed:

“They compared him to their other grandson that was born after mine. My mother-in-law was heard to say that she has one perfect grandson and one that’s not so perfect, and the person who heard her, came back and told me, and I laughed at them and I said yes, my son is perfect, because he is mine.”

Ana further said as she recalled her conversation with the principal of the school, that she would be fully responsible for anything her child needed or wanted while at school: *“I will be willing to stay with him on the compound, and sit outside, you know and I will be responsible for him to take him to the bathroom to help do anything, I am there”*.

As I refer to the concept of ownership, speaking of death, Sherma recounted:

“I have a special child. But she needs plenty more care than the ones who are not and I told him [her non-disabled son] that already, she must be well taken care of, but I know if I die Val will die too. She will die shortly after me, that is how I feel as a mother, because since [her father] died she sleeps with me. Since he died, I have nobody to be close to her. My child, she depends on me”.

There were three occasions in the interview that Sherma spoke of her death and expressed that she felt that her daughter will die soon after her. Prabha on the notion of death similarly expressed the following:

“Sometimes I does [do] lie down by myself and think about if I am dead. But I’m happy that Kate has a daughter, and I does[do] talk to the child and I tell her that if your grandmother [is] dead you must take care of your mother and see [that] nobody [takes] advantage [of] her, ok? And she [the grandchild] always talk about that. That’s the only thing I have in my life, only thing in my life, my daughter.”

Ana spoke of death and hope for her son in a more subdued tone: *“I will like to think that he can cope and manage without me being around.”*

In my view, protecting their children from harm or death was another factor inextricably tied to the concept of ownership. As the mothers probably viewed their children as an extension of themselves (Pierce et al., 2003), it follows that they may be inclined to protect that part of themselves (their children) from harm, because harm to their children is like harm to themselves. Regarding the protection of their children, the mothers expressed the following sentiments. Prabha recalled: *“it’s important for children like that, to make sure, that when they grow up, nobody can take advantage of them. They have their own sense so that no disability or nobody can take advantage of them”*. Ana also commented, *“to me the goal is to be able to take care of yourself, within the parameters that society has set, I worry that he will get taken advantage of.”* Sherma recounted, *“knowing the society we live in, knowing how people are, I don’t know I wish that nobody harms her. As a mother, I don’t want anybody to harm her. Because my child is a loving child”*.

4.4.4 Discussion on Ownership

The findings indicated that the mothers raising disabled children in Trinidad and Tobago had a difficult time in parenting, and protecting their children. Expressed in her particular way, Prabha for instance spoke about the extreme difficulty in terms of cost, time and effort that she experienced in raising her child, and she repeatedly spoke about doing it alone. She emphasized that she was the only one responsible for *“making”* her daughter *“what she is right now”*. In other words, she took full credit for her daughter’s successful development as she felt that she *“owns”* that credit. Ana also alluded to the concept of ownership as she felt that her son adopted his good behaviours from her since he spends eighty-five percent of the time with her. From the interviews, it was learned that both Sherma’s and Ana’s children had severely delayed development, Ana’s son having the mentality of a three-year-old while at a chronological age of nine and Sherma

having a forty-year-old daughter at the development age of twelve. Prabha's daughter was twenty-five years old and her development was normal, but she was categorised as hearing and speech impaired. Therefore, all these children needed a constant level of close protection.

As their children were not of the prescribed development age, mothers may have perceived their adult children as being small children for the rest of their lives, which can create mental and emotional stress for them (Raff et al., 2021). Hence one can understand why they will want to care for their disabled children until they die. A more pertinent thought to consider may be whether mothers of disabled children can consciously neglect their *little children* who happen to be living in an adult body. Can mothers purposefully leave their vulnerable children in a perceived stigmatizing world that can harm or “take advantage” of them? The findings point to a negative answer to these questions. Algood, Hong, Gourdine, and Williams (2011) pointed out that disabled children are less likely to be heard and more than three times prone to be abused than non-disabled children. It is therefore understandable why all the mothers in this study firmly expressed fears concerning the disadvantages their children could face by being impaired or disabled in Trinidad and Tobago. In this regard, one of their goals was adopting the role of a lifelong protector for their children, which is itself a demanding task in their caregiving roles.

The need to protect their disabled children can emanate from mothers knowing that their children are more vulnerable or more likely to be mistreated or abused even by family members (Sullivan & Knutson, 2000; Jahng, 2020; Shah, Tsitsou & Woodin, 2016). Therefore, I think that the mothers wanted to constantly guard their “property”, with the intention that no one else could lay claim to the possession of their children's fragile minds and bodies. Prabha for instance expressed the horrible trauma she lived through when her daughter was sexually abused and the anger she felt towards the perpetrator. She recalled: *“I ended up threatening that ‘fella’ [fellow] and I told him I will kill him.”* Mothers can carry an added fear when they have female disabled children for whom they care. In the Trinidad and Tobago society, there are reported increased rates in crime, abduction, rape, and other sexual offenses. For instance, the Inter-America Development Bank Report on Crime and Violence in Trinidad and Tobago reported that during the period 2009 to 2013 there were 13,168 reported cases of rape, together with other sexual offenses, and only 8,325 or 63.2 percent were detected (Seepersad, 2016).

This is relatively high for an island with a population of 1.4 million. Thus, the impact of this constant care burden and the need to be continuously vigilant for disabled children and in this case, female disabled children can generally be damaging to the mental well-being of mothers. Furthermore, as single parents, the burden of protection was greater for two of the mothers in this study who raised disabled daughters.

As previously mentioned regarding ownership, mothers view their children as an extension of themselves (Pierce et al., 2003) absorbing the disability and making it part of their identity (Landsman, 1998). From discussions in Chapter Two, I mentioned that mothers experienced both the subjective and objective burden of care; Hassan et al, (2021) defined the objective burden as the daily interrupted life routines resulting in limitations to the social, occupational, and family life resulting from a child's disability, while the subjective burden is the reactions from mothers stemming from the psychological factors such as anxiety, frustration, and depression (Hassan, et al., 2021). For this reason, I believe the mothers in this study could not separate themselves from their children and if they did, it could not be for a substantial period. Although the mothers did not overtly express that they owned their disabled children, through their sacrifices and their role as defenders and protectors, I inferred that they felt like the owners. It is my view therefore that this *split identity* of mothers makes them assume a subconscious double role of protecting both themselves and their disabled children whom they feel belongs to them and are part of their own being. Hence these assumed ownership feelings mothers had resulted in the mental anguish and subjective feelings they constantly lived in their caregiving experiences. An example can be drawn from Prabha's grief statement when she said, she cried "*night and day*" when she learned her child had a disability.

While I present the findings suggesting that the mothers "own" their children, I also pose another challenging consideration, the question of whether the disabled children own their mothers. According to Beizer (2002) who spoke of her adopted daughter in an affectionate tone, said: "like most parents ... I am utterly possessed by my child. When I am away... my body is as disoriented as if it has lost a limb. When my daughter performs at school, I feel a burst of recognition" (p. 248). This author was obviously taken by her child, much in the same way the mothers in this study felt and I myself sometimes feel towards my own children. The mothers' own well-being was secondary when compared to that of their children in this research. It is as if they had surrendered to the children's

every need or demands, the children who “own” them mentally and physically. Since they are children, they would not know the effect they have on their mother’s emotional state as they cannot rationalize their behaviour, so evidently, they would be innocent. Therefore, mothers had to find the strength to be resilient, to exercise control over their emotions despite how their children reacted, which can be challenging on their psyches.

I have not found much literature to probe the notion of children owning their parents, but to me, and from personal experiences, I know child nurturing can make a mother give up or want to give up their lives to care for them, especially if children have a long-term illness, a profound disability or a serious health condition. Pierce et al. (2003) noted that children from as early as age two understand the concepts of “me” and “my” and begin to own and want what is theirs (p.3). They associate these concepts with whoever has control, whoever takes care of them, and hence they can, to some degree, psychologically control their mothers. Children with mental disabilities may not have the ability to reason the negative impact their demands may have upon their mothers. They can therefore make parents feel guilty “by duress” given the permanence of their impairment. Sherma expressed how she always felt guilty when her daughter became angry. This mother tried not to react in frustration or annoyance to her daughter’s outbursts, and the self-control this required was taxing on her mental health, to say the least. As she recalled, she had to “cool” herself at times. It brings to mind what I discussed in Chapter Two where Harvey and Long (2018) spoke of the ‘unshareable’ ambivalence and abject thoughts the mothers in their study shared about their disabled children. Given the context of Trinidad and Tobago and the ‘closed door’ attitude to disability, I felt that that the mothers may have withheld speaking their dark thoughts, if they had any, about the care burden of their children. Even with me as a researcher, whom they came to trust, they were careful in divulging really innermost thoughts particularly if they were on the “darker” side of caregiving. Ana as well, said she had to give up many of her interests for her son’s sake, noting that her life “revolves” around him. She recalled:

“It has limited my amount of social time when my focus shifted from being social to being mother of a disabled child, who very rarely went out. Because of his illness and his disability, I actually stopped working.”

It does seem to me that these children “own” their mothers, from the point of view that the mothers may feel they are not doing enough, or they shirk their care responsibilities if they were to leave their children and engage in activities that interest

them. The psychological impact, therefore was exorbitant on mothers in this study, not because they feared what would happen to their children if they did not submit to their (children's) demands, but rather because of the guilt that they felt for creating a disabled child who they may regard as, their extended selves (Pierce et al., 2003), or, to put it in layman's term, their own *flesh and blood*. Battling these emotions of pleasing their children and wanting to please themselves are contradictory feelings of ambivalence or abjection that Harvey and Long (2018) studied. This conflicting state of mind can situate mental anguish on a mothers' psyche which can increase their care burden, stress levels, and the likelihood of falling into depression.

Pierce et al. (2003) spoke about the concept of "psychological ownership" (p. 6) meaning that human nature is territorial, which stems from both biological and attitudinal factors. These authors confirmed that one's possession is part of the "extended self" (p. 2-3), in that people become attached to what they create and own. Their belongings, therefore, become part of their identity, whether in the form of physical property or people (Jeske, 1996). Psychological ownership is a very relevant concept for mothers in this study because of the sense of possession they felt having created their disabled children (Jeske, 1996; Landsman, 2005).

As discussed in Chapter Two, the intimate relationship the mothers had with their children and the affective component, that of maternal love (Kikuchi & Noriuchi, 2015) caused them to feel this sense of ownership and control over their children. Therefore, having this intense parenting relationship with their disabled children (Zulfia & Allenidekania, 2020; Woodgate et al., 2015), in my estimation, makes the guilty thoughts more provocative or more pronounced to the point that it seduces mothers, owns them, and continuously makes them stand on constant guard for their children. As a result, I believe that these mothers who sacrificed much of their lives to care for their children should be understood, assisted, and respected. They deserve recognition and should be entitled to a balanced life so they can function optimally in their caregiving journey. Hassan et al. (2021) note on this subject, that recognition of one's abilities encourages a state of wellbeing where individuals can be "better able to cope with the normal stresses of life, work productively and fruitfully, and make contributions to their communities" (p. 63). However, recognition of mothers' caregiving roles can only come from understanding disability from the mother's perceptions and experiences. Therefore, if

ordinary citizens like myself, family members, community, and government can appreciate this aspect of mothering, they may be more inclined to support mothers and their disabled children. This understanding may result in creating a more equitable and less burdensome life by reducing the psychological extremity of their caregiving demands.

As presented in the findings above, one of the concepts that emerged from the data was the idea of death or dying. The concept of ownership aligns itself closely with these morbid thoughts. The mothers spoke of their pervading thoughts about mortality in different ways. Prabha, for example, related how ubiquitous her thoughts were on death, and to me, this had a stressful impact on her mental state. She recounted that she spoke often to her six-year-old grandchild asking her to take care of her mother (Prabha's daughter) if she (Prabha) should die. My perception here is that Prabha was more focused on her daughter's wellbeing and safety than placing such a heavy burden on a six-year-old non-disabled child. Such constant thoughts about one's future demise defined as "mortality salience" can affect a mother's mental wellbeing particularly since her caregiving involves such heavy emotional output (Trémolière, De Neys & Bonnefon, 2012, p. 379). Sherma repeatedly said that she knew her daughter would die soon after her and, in my view, spoke almost as though she hoped this would happen. Ana wanted to get her child to a place where he does not need her. As mothers are closest to their disabled children (Harvey & Long, 2018), the encompassing intense maternal fears affect mothers' behaviour towards their children which can impact negatively upon children's own behaviour (Sinason, 2002). The children can become deviant (Hassan et al., 2021) or disruptive by absorbing the fears from their parents. For this reason, it is important to lend psychological or emotional support to mothers of disabled children.

Mothers carry a heavy burden of worry about their children's future survival if they should die before their children. While this is understandable, given their actual experiences with disability in the Trinidad and Tobago context, I would like to provoke the thinking that from a psychological perspective, do mothers' perceptions surrounding dying and death stem from a basic human nature to be selfish? Could it be that because they claim ownership over their children (Jeske, 1996; Beizer, 2002; Pierce et al., 2003) they secretly wish that they (their children) die first so as not to leave their children behind to "suffer?" (Landsman, 2009, p.18). Or could it be that if the mothers should die first,

they will lose the control they have in caring for their children? I found that the notion of death, in this instance, relates to the idea of control (Pierce et al., 2002). As I explained in Chapter Two, mothers subsumed the identity of their children (Landsman, 2005) as their own. They may think of their death as if it is their children's death. From a personal perspective, they may not want that part of their "legacy" (their disabled children identified as part of their own being) which they see as stigmatized, pitied, or laughed at, to be left behind. The control mothers will have to relinquish when they die is not something they may wish to pass on to others who they feel will never truly understand the worth of their children's lives (Landsman, 1998; Goodley & Trekgaskis, 2006; Lalvani, 2011). These feelings are referred to as the subjective burden (Harvey & Long, 2018; Hassan et al., 2021) which can manifest itself in the selfish dimension of sorrow and grief, so to speak, that makes mothers want to *carry* their most precious possession with them to their graves.

Facing these very morbid and almost dangerous thoughts such as those that lead to filicide or mercy killing discussed previously, which Pierce et al. (2002) call the dark side of "psychological ownership" (p. 30), is a psychological fear factor that points to the consideration that mothers need assistance in coping. They may benefit from counselling to deal with this subjective burden of care stemming from the question that haunts them the most: who will care for my child after I die? The psychological battles these mothers experienced were probably borne out of maternal love (Kikuchi & Noriuch, 2015) or the thought that people do not value their children (Lalvani, 2011), or that they are perceived by society as less than human (Kristeva, 2013; Goodley, Lawthom & Runswick, 2014). By having psychological support, mothers may adjust their "selfish" perceptions and heed the words of Beizer, (2002) who cited Goodman (1993) as saying, "our children may be our own, but we can't claim ownership. What I have learned is that...we must learn to share children. We share them with the world. But most particularly, we learn to share them with themselves" (p. 248). In other words, society, culture, and tradition also have to be sensitive to the upbringing of disabled children. For this reason, health professionals, government, family members, and even other mothers themselves should seek to understand the experiences of mothers of disabled children so that they can provide better care for the nation's disabled children.

4.4.5 Maternal Self-Efficacy

Thus far, I have discussed in detail the way mothers perceived their responsibility from the personal and psychological perspective of ownership. Continuing to address research question two, on mothers' perception of their caregiving roles, the findings reveal that sometimes their overprotective disposition, fears, and distrust of others can be extremely pertinacious. They may perceive their caregiving responsibilities can only be done by them, making them the most competent and efficacious (Koch, 2020; Hassan, et al., 2021; Pierce, et al., 2003). To this end, I address this second research question by exploring the findings pertaining to competence and maternal self-efficacy in mothers carrying out their caregiving roles.

Mother as Financier - The mothers in this study assumed the role of the major financier, with the help of their spouses. In Prabha's case, she depended on limited public support as her husband had died and she had no one else to assist her in providing for her daughter. Prabha shared her struggles:

"I had to look for milk, I had to look for pampers. It was really hard. Then they [Government] send we [us] to a school in South, but it was \$500.00, so I couldn't afford to pay that. I barely had money for myself, I did without many things, even food".

Speaking about providing for her daughter's future needs, Sherma also recollected:

"My older son would have the full support because I give him this property, all my money is invested here, all that is my money that I have to give him, so he can take care of Val. It's better you not worry, when that bridge reach, whatever happens will happen, and I have secured Val financially, if I'm not here to support her."

Similarly, Ana shared her experience about her son:

"He gets the attention that he need, but at a cost financially to us, it's not cheap, and every term you have to pay the fees, not just the school fees but whatever other fees, because you have no alternative for your child. My husband bears the full financial brunt for all our medical expenses and there have been a lot. Because of his illness and his disability, I actually stopped working. So you have to prioritize, you stop fancying up your house, you stop going out to 'lime' (hang out), on vacation, you stop buying clothes, you wear the same shirt 6 days for the week".

Mother as Educator - With regards to adopting the role of a mother-teacher (Cole, 2012) to ensure their children had an education, Ana recalled: *"I am not an educator in the*

formal sense, I have not been trained in Special Education, I could be wrong, I could be doing it wrong, but I did what I felt was common sense.”

Sherma related her experience as well regarding schooling her daughter:

“I did encounter problems...but she has her life skills and she is a good child; she doesn't mix with outside people. She knows everything that is taking place, she reads the Guardian [newspaper] every day, looks at the world news, likes a little soap[opera], her puzzles, and she is really up to date. And we teach her every day, she learns.”

Prabha also shared her experiences:

“So I have to help out Dena [Prabha's granddaughter] with the home lessons, because one minute her mother's feeling good, next minute her mother don't [doesn't] be feeling good. That's why I don't leave Kate much. I never left that child with anybody, even in school, when we go to school, I used to stay in the morning and all day until time to come home, because it was very important for a child, like that child, to make sure, when they grow up, that nobody can take advantage of them. They know to read, they know to write, they have their own sense that no disability and nobody can take advantage on them”.

Mother as Nurse -Apart from being the in-house educator, the mothers' roles also included that of a nurse and manager, particularly for Ana as her son had perhaps the most severe illness of the three mothers. She expressed:

“I have one very good friend that I will feel confident, more so now, that I will leave him with for a couple hours. That being said, it will always be between his medication time, as I don't trust anyone to give him his medication. With his health issues as I said, school just wasn't a day to day occurrence.”

Prabha also told:

“When she was small, and let's say you give Kate something, she used to make sure she smells it, know what to do with it, that's how she used to carry on when she was a baby. Even though somebody give her something, she smelled it, throw it away because she never took nothing from nobody”.

Sherma also recounted:

“I have a special child. But she needs plenty more care than the ones who are not. She is little bit slow with her speech and little tardy, but you know, I manage all of that, because I give myself courage to do what I have to do.”

Mother as Advocate -In Chapter Two, I reviewed the role of advocate that mothers assumed in their caregiving roles. In this regard, the mothers expressed their feeling that aligns with advocacy for their disabled children. Prabha proudly expressed: *“I could go*

up on a platform and talk about my daughter, because I know the trouble I see for her and how nobody doesn't care about children like them".

Ana also gave her views:

"I think it needs somebody who is not a politician to push it forward... somebody who has a passion for the cause itself, as opposed to having a political agenda behind it. And a person with a disability has so much to give, they have so much to teach "normal" people. The student with disabilities, always seemed to be kinder, always seem to be more patient, always seem to be more loving than a quote, unquote 'normal' child."

Regarding the way, the mothers in this study judged or perceived their multiple roles, overall, they felt that no one else may be qualified or competent enough to care for their children. Ana spoke at length about her undying efforts to care for her son and the research she conducted about her child's illness and disability.

"When you have a child that's ill, you don't want to push him, you don't want to physically exhaust him to the point where he gets ill and he's down for days, you have to pick and choose your battles, you say okay, today is a good day we're going to go today, tomorrow might not be a good day, we will have to stay home and rest....Yes, who will take the time to learn to deal with Kris, who will take time to go online to read about his illness, who will take time to say "hey you guys alright?", if you guys need a break, Kris can come and stay with us for an hour, you and your husband need a little alone time. You know I mean, my husband and I are both very able we don't leave him with anyone, he goes wherever we go, if he can't go, we don't go".

Prabha, in describing the trauma her daughter went through after she became pregnant, spoke of the child's father: *"well, he didn't want to pay. Then I take [took] him to High Court, so he had to pay the maintenance. I had it really hard; from [the]court, we had to go [to]Legal Aid and then to [the]Family Court; so it was really difficult for me to manage."* Sherma spoke of her extended efforts, her fears, and how she feels about her responsibilities towards her daughter:

"If we didn't take care of Val, she would've probably gone astray. Children like those go astray very quickly, with friends, influences, and stuff. I have learned to accept my child and I know it's a challenge, and I know I am a kind of a brave person with an open heart, you know. And as I tell you, it does not bother me, I just feel sorry for her, like, I don't like to talk about it when she is there, but, anything she wants I give her, I don't like her to be angry."

Sherma also recalled her lifestyle: *"I am not a person who mixes a lot, I am a homely person, and me and my husband live a simple and quiet life. Not too much parties, maybe two parties for the year, a little outgoing, a little beach, with her."*

4.4.6 Discussion on Maternal Self-Efficacy

In Chapter Two, I referred to parental self-efficacy as feelings of competence that can account for “positive parental outcomes” (Kuhn & Carter, 2006, p.565). Mothers in this study, as research has found, assumed multifaceted roles (Tsai, Tsai & Shyu, 2008) in their caregiving journey. As a result, they may feel they are the only ones who can fulfill these excessive caregiving roles. They may think that there is no *one* person who can “humanly” do or *want* to do what they did and continue to do for their children. In this research as confirmed in other literature (Pillay et al., 2012; Collins & Coughlan, 2016) the findings of the data indicated that mothers are their children’s main caregivers and nurturers. They also fulfilled the roles of educator, financier, advocate, manager, friend, and nurse all rolled into one. Having to carry out these extensive caregiving roles limited their participation in other activities which typical mothers would have usually engaged (Dehghan et al., 2015) such as paid work, going to parties, or other leisure activities, or even advancing their own education.

While some may argue that most “good mothers” (Kim & Hwang, 2019, p. 1201) would perform the same caretaking roles for their children, I present here that the roles of the mothers in this study are unique in that they function at great expense to their mental health. Their care burden is more cumbersome, financially, emotionally, and socially (Hassan et al., 2021; Gona et al., 2018). Additionally, they have to find the time to provide for social and developmental activities for their children. As Ana pointed out, her social circle became extremely limited. Sherma also said she lived a ‘*simple and quiet life*,’ and has become a ‘*homely*’ person, and Prabha was too economically burdened to find time for much leisure. The only time Prabha spoke about a social life was whenever her daughter was involved. Yet still, these mothers had to be their children’s social support, their friends, and their confidante. Sherma explained how she talked to her daughter every day, and learned a lot from her. These mothers fulfilled their roles amidst the uniqueness of circumstances involving social stigma, reduced relationships, and limited social support. One can therefore conclude, as I discussed in Chapter Two, that mothers come to view themselves as mini experts or “experts by experience” (Gona et al., 2018) in caring for their disabled children or those with long-term illnesses.

In the journey of their intense caregiving roles, mothers took pride in their children as they see their work merited by their labour in managing their children's disability (Pierce et al., 2003; Beveridge, Berg, Wiebe & Palmer, 2006). From a psychological perspective, Pierce et al. (2003) noted that psychological ownership discussed above is a complex phenomenon that consists of a cognitive and affective core. This means mothers become aware of their children's condition through intellectual perception as well as a feeling of pleasure of being the "owner" of their children. These feelings as Pierce et al. (2003) note are usually accompanied by a sense of efficacy and competence (p. 5). From the findings, the mothers saw themselves as the only ones capable of caring for their children. For example, Ana would not let anyone else administer medication for her son. Prabha would not allow anyone else to feed her child and Sherma, apart from her husband, never left her daughter once with anyone else. Ana also said that there was no one who would "*take the time*" to learn about her son's illness or to research it "*online*". Although Sherma did not use the actual words, she did suggest that her daughter's temper was something that no one else could manage but her. Therefore, mothers perceived everyone else as incompetent. Having to manage and live with their children's disability, they came *to know* and understand the impairments, their children's behaviours, the treatment regime if the child is ill, as well as the disabling societal factors that acted as barriers to their children's functioning (WHO, 2011; Oliver, 2013; Degener, 2014) abilities and inclusion. Thus, based on the mothers' unique caregiving circumstances, their multifaceted roles, and self-trained expertise in the cognitive, and affective domains of caregiving, the mothers perceived that they are the most competent, and therefore the most effective in offering care.

The mothers' feelings of competency and efficacy can also be demonstrated by their roles of being their children's teacher and their voice or advocate. Being an advocate in this instance is closely tied with the role of protector discussed previously. The three mothers in this study all knew that their children do not have the capacity to enforce their own rights, speak for or protect themselves and hence they saw the need to guard against other forces that may compromise their children's life. Hence, they were their children's voices (Ryan & Runswick-Cole, 2009). While these mothers were not activists or choose to go public with their experiences, participating in this research can be considered one way for mothers to advocate through their stories which can reach a wider audience. As Isgro (2015) maintains advocacy for mothers pertains much to "the one-on-one battles

that exist in the daily lives of their children” including having to negotiate with various professionals that their children have “comprehension and agency” (p.77).

In demonstrating their thoughts on advocacy, the findings indicated that Ana for instance thought that one must be genuine in their effort to fight for the rights of disabled children. She spoke on behalf of her son and other disabled children, that they have valuable contributions to make if given an equal chance, even if it was in behaviours that demonstrate kindness and love towards one another. Prabha felt she can speak on a “*platform*” about her daughter’s success in functioning. Sherma as well, the most subdued of the three mothers, spoke about the success she had with her daughter being able to do things for herself and learning about various things from her daughter. Advocacy for the mothers in this study was difficult to do in the usual way. In this regard, mothers had to find the strength within themselves to speak and defend their children through the hurdles in their journey with disability, which usually goes unnoticed by society. However, Woodgate et al. (2015) believe that it is important for others to be aware of the work involved in parenting a child with special needs. Nevertheless, since the recognition by others was absent, mothers found greater efficacy and motivation by the recognition of their own efforts and by speaking about them. I also think that sharing their stories with me, which was a first-time experience for all of them, was a positive experience. It brought their own self-identity (Ryan & Runswick-Cole, 2009) using their own language (Isgro, 2015) into the realm of positivity by showing up their children who they raised almost single-handedly, as worthy, loving, and compassionate human beings (Landsman, 2005; Lalvani, 2011) and of whom they were proud.

Maternal self-efficacy also came from the mothers’ role as educators. Adopting the role as “mother-teacher” (Cole, 2012) in the absence of opportunities for formal education, the mothers home-schooled their disabled children so that they can develop a level of independence. Mothers were comforted by the hope that their sacrifices would result in a greater chance of survival for their children in a disabling environment. The mothers also saw home-schooling as an avenue to guarantee a degree of safety, a means of preventing any possibility of ill-treatment, abuse, or discriminatory interactions toward their children while under their direct care and guidance. Ana, talking about her son, remarked “*the only place Kris can be himself one hundred percent is at home.*” Schooling, however, will be discussed later in greater detail. The mothers’ self-efficacy

came from the assumption of multifaceted roles in their caregiving journey as well as the perception that they were the most competent or the experts in caring for their disabled children.

4.4.7 Self-Efficacy and the Nature of Disability

In this research, I found that the mothers' perception of their roles was influenced by the nature of their children's disabilities. This study did not focus on any specific type of disability; I explored mothers' experiences with having a child with *any* disability. Based on the uniqueness of the mothers' experiences regarding caring for their children, I examined the specific disability each encountered in caring for their children. I felt that it was worthy to see how they perceived their caregiving roles and the extent to which each mother extended herself. While reviewing the mothers' stories, I realized that each mother had a significantly different experience. In my own reflection, I generalized what it meant to have a child with a disability or a combination of disability and long-term illness. I felt that the mothering experiences would be similar once a mother has a disabled child, regardless of the disability. However, in analyzing the findings of this research, I found this to be a very biased assumption on my part and one that needed to be changed. I also think that knowing about specific disabilities is important as it can help us to understand the intensity of the caregivers' experiences so that the right support can be given. In this regard, I present each mother's story and situation individually for clarity.

Ana's Story

Ana's son had a rare disability called Dravet Syndrome. Jensen, Brunklaus, Dorris, Zuberi, Knupp, Galer, and Gammaitoni (2017) explained that Dravet Syndrome (DS) is an acute and very rare type of epilepsy that surfaces within the first year of a child's life or even at birth. These authors reported that it is estimated that DS happens to one in every 15,700 live births in the United States (US). The children develop "febrile and afebrile generalized clonic or hemiclonic seizures... myoclonic, focal and atypical absences and the epilepsy is usually resistant to treatment" (p. 4). In non-medical terms, this means the child can develop a high fever with seizures making his body jerk uncontrollably. The authors also noted that there is a high risk for mortality and sudden unexpected death resulting from epilepsy. In a study done in Germany they also stated that the direct cost burden for parents was on average, US \$14,500 (in 2011) which is equivalent to \$101,500 Trinidad and Tobago dollars, in the first year of birth which does

not include indirect costs such as transport or accessories. Jensen et al. (2017) also noted that little literature is available on this rare disease. In Trinidad and Tobago, there is no formal research on DS available to the public. However, a Google search revealed that there is a non-governmental group called The Seizure Awareness Foundation of Trinidad and Tobago, that tries to raise awareness of the disease. In fact, Ana revealed that her son was not diagnosed in Trinidad but in Miami. As I presented earlier under the section above on diagnosis Ana painfully recalled doctors could not find the cause for her son's illness. She said: *"thank God, my husband's promotion has enabled us to pay our bills, especially the medical bills because as with Educational services, Medical services were not available for my son."* These experiences had a profound impact upon the humanistic and financial burden of Ana and her family which as Jensen et al. (2017) said, can "contribute to greater psychological and health problems among the caregivers of children with DS" (p. 2). The idea of a rare illness that has no cure and a high infant mortality rate places added stress on this mother. Children who suffer from this illness experience irregular sleep patterns and a range of other health problems (Jensen et al., 2017); this suggests the extent of the mother's care burden and the mental and physical exhaustion generated as a result. Living in a society such as Trinidad and Tobago that has little to no research on this area of illness and on disability in general (Charran, 2018; Roopnarine et al., 2015), where doctors could not diagnose Ana's child's condition, placed a huge burden on the mother. It represented a type of hopelessness and fear that Ana continues to live through. It is understandable then why she may claim "ownership" over her child as she sees no one else, not even doctors, who could adequately assist. Such a situation calls for consideration in this field of childhood disability diagnosis, which to large extent should be a function or responsibility of the state.

Sherma's Story

Sherma's daughter was diagnosed with delayed development and early detection or intervention was not something that was given to Sherma. In fact, the child was diagnosed at age six. According to Roopnarine et al. (2015) in the Caribbean context, children with developmental delays are usually labelled as "hardened" (stubborn), troublesome, and difficult or non-compliant (p. 230). These authors suggest that in the Trinidad and Tobago context generally if parents accept that such children are difficult to manage or unable to learn, they would be less likely to provide the appropriate "cognitive

and social” developmental stimulation at home (p. 230). Sherma spoke of her child’s anger and the inability to control her behaviour at times. She further added that at the time, which was approximately thirty-five years before the interview for this research, there was “*nothing in place for my daughter*”, indicating both medical diagnosis and institutional or educational care was unavailable. Sherma admitted that maybe if she had a more advanced level of support, her child’s development would have been more advanced.

Prabha’s Story

Prabha’s daughter, as indicated previously, was hearing and speech impaired diagnosed at age two. This was a rather long time before the diagnosis of a hearing disability. It points to the level of medical care or the lack thereof twenty-five years ago in Trinidad and Tobago. According to Colledge (1949) when deafness occurs in childhood the psychological problems involved are intensified (for both the child and the parent). Colledge further indicated that intelligence, knowledge, mental habits, and social attitude would not have yet been developed in the child. These developments are usually dependant on the ability to speak and to understand speech which is how the child acquires knowledge. This was what Prabha feared when she observed that a child such as her daughter needed to know how “*to read and write*” indicating the importance of education or knowledge. Naturally, as the data showed, Prabha sacrificed her basic needs to ensure that her daughter was schooled. A more menacing thought for this mother, as Colledge aptly described, is how her hearing-impaired child would be able to:

“Think without words, conform to a code of behaviour without reasons or explanations, follow activities without clear directions, mix with other children without being able to play freely with them, live the life of a child in circumstances suitable only for a recluse.” (Colledge, 1949, p. 391)

In a more recent study amongst Arab mothers of deaf children, Alhuzail and Levinge (2018) found that mothers are usually isolated, have to provide the warmth and love for their children whilst coping with “prejudice, revulsion, and harm” and the stigma and ignorance from the wider community (p 385). This can be demonstrated from Prabha’s experience in facing the stigma, not only towards her daughter but towards herself as well, which resulted in her violently beating a woman for calling both her and her daughter derogatory names. Concurring with Alhuzail and Levinge (2018), mothers had to be the protector of their deaf and speech-impaired children and their advocate at the same time.

From the way I see it, all three mothers had equally difficult experiences in raising their children and dealing with the specific type of disability. However, I think that Ana had possibly the most difficult time in coming to terms with her son's condition because of the severity of his illness. The fear of her child dying at any given time is possibly the most stressful experience for any mother, and I am speaking from the perspective of a mother who also had a very sick child. Prabha and Sherma both had their equal share of "troubles" despite their children not having a long-term illness. This is not to say that they were less worried about their children's future. For example, Prabha shared her experience regarding the sacrifice she made: *"I was five going on six months pregnant and I went and had an abortion just to take care of that one child."* Children with hearing and speech impediments can adjust, as Alhuzail and Levinge (2018) purported; they live an almost normal life if they have the right support. Sherma, however, had almost resigned herself to having a child with a disability as an act of fate or as the moral model of disability suggests (Retief & Letsosa, 2018) an act of God. She recalled:

"There are children who are worse off than mine, so that is what gives me courage... when I look around and see children with disability, I will say thank you, Jesus, my child could see, she could walk, she could talk, she has basic life skills".

In my view, both Sherma and Prabha were more worried about their children's education and safety. I noted, however, that while Prabha and Ana were both more aggressive in their outlook to public perceptions of disability, Sherma was not. One reason could be that she was much older (over seventy years) than the other two mothers, and her daughter was the oldest of the children as well. Essentially, she had been living with the disability of her child for over forty years compared to Prabha (twenty-five years) and Ana (nine years). Sherma's level of acceptance was, therefore, greater and her outlook in life was possibly more philosophical in that she believed it was God's Will for things to be as they were. This, she said gave her courage to go on, the belief in God and the acceptance that she could not change what life had offered her.

All mothers had to contend with isolation and stigma, but Ana worried constantly about whether or not her child would live or die. It brings Kristeva's (2013) powerful connotation of mortality and human finitude to mind:

“The so-called solitude of the disabled person has inevitably an absolute companion, a permanent body-double: the pain of mortality. Even if this person is not sick, even if they do not feel specific pains, their disabilities remind them permanently—they or at least those around them if the deficit deprives them of this consciousness—that they are not like others, who are able not to will to know that they are mortal” p. 225).

In this research, the findings reveal that mothers thought about their children in terms of their own death, hence their reality was structured around the needs of their children while thinking about death. Such trauma, as I pointed out in Chapter Two, can affect a mother’s self-efficacy as she may perceive her role as difficult and unmanageable (Kuhn & Carter, 2006; Al-Kandari & Al-Qashan 2010), engendering a kind of hopelessness in her mothering role. It is my view, therefore, that there should be sufficient recognition and support for these mothers as they battle with their children’s disabilities and their lives while striving to become resilient to the daily caregiving stresses. Therefore, the type and severity of the disability a child has will impact the quality of life (Alhuzail & Levinge, 2018), the psychological wellbeing, and the emotional state of their mothers. In this regard, the mothers’ perception of perceived support or perceived stigma can either assist or reduce her self-efficacy and care burden in her multifaceted caregiving roles.

4.4.8 *Maternal Perception of Cause of Disability*

In discussing maternal perception, I will discuss stigma, self-blame, and God’s Will as they relate to the causes mothers may internalize for their children’s disabilities. I examined these concepts with a more psychological focus on why and how mothers come to view their caregiving responsibilities. The way the mothers perceived their roles could hinge on what they considered was the cause of their children’s disability. The findings revealed that mothers saw the cause in different ways. Sherma spoke about religion:

“Religion had nothing to do with it, I just for myself, me as a person, I feel I have to be doing what I should. God knows, I never questioned him, because I go back to the same thing I keep saying, there are parents with different, entirely harder children to live with than me. They cannot do as much, so that is my courage, that is what I live for. I am not a Christian but I say thank you Jesus. I listen to Joyce Meyers [a spiritual preacher] because of my child; she listens to Joyce Meyers every morning at six, and I am there with her with my coffee, and we sit there together.”

Ana spoke of the cause of her child’s disability as it pertained to her employment:

“I was working long hours, ignoring my health, and then I had to be rushed to the hospital and when he was born they said he had a lack of oxygen to his brains and

that is what could cause his illness and disability. And it was said after my son was diagnosed, that I was too modern for the Hindu beliefs, that everything I did came back tenfold to me, referring to my son and his disability, he was called 'broken'."

Prabha also recounted an incident that took place regarding the perception of what caused her daughter's disability.

"I end up in court. I fight with people. It had [There was] a woman next door by me, she used to 'drop' words, [saying] I can't make a good child and look at the kind of child I made. One day I [got] fed up [of] hearing this woman, passing by my door only dropping insulting words. Well, I waited for this woman one day, and I hold[held] her by [her] head and 'well' beat her. I had to go in Court now and pay for beating the woman for troubling my daughter. That's why I tell you I don't joke with [when it comes to] my daughter, because I know, how I make [made her] and how I mind she [took care of her]."

Regarding the notion of stigma, Ana commented on the use of language to describe her son and disabled persons, generally in Trinidad and Tobago:

"Because there is a stigma attached to being retarded, alright, and my son has been called retarded, and it's a terrible word, and there are so many of them in society, and people don't see them, because of the stigma that is attached to that child. People don't talk about it when people don't see it. Even when people see my son, and he starts to talk or if he gets fussy, people think about something is wrong with him, but they look at him funny. They never ask a question, okay, what's wrong with him?"

4.4.9 Discussion on Maternal Perception of the Cause of Disability

The findings revealed that three factors are linked to what mothers perceived as the cause of their children's disability: the stigma that mothers are the cause of their children's disability, self-blame, and God's Will. In Chapter Two, I referred to the notion of stigma and its effects on mothers' psychological wellbeing. Stigma refers to the negative attitudes from people that potentially result in negative psychological effects on individuals who are stigmatized (Goffman, 1963; Hassan et al., 2021).

The mothers in this research experienced stigma and "courtesy stigma" (Goffman, 1963) or some writers call it "affiliate stigma" (Hassan et al., 2021), which is the stigma ascribed to individuals who are in close contact with disabled persons. Hassan et al. (2021) noted that it is this internalization of the stigma by parents that causes a greater family burden in their caregiving role. As Ana pointed out, mothers had to deal with thinking about "what people will say" about their children. They may also have to deal

with snide remarks, curious stares, or even offensive questions (Nazzal & AL-Rawajfah, 2018). Ana in relating the abuse she got from a close relative about being the cause of her son's disability recalled, *"it did hurt at the time, but then I think to myself, you know, I'm a good person, I did do at that time what was considered right."* Prabha also recalled how others question her about her daughter: *"people say how she is so beautiful, why she can't talk and why she can't hear? How come she [was] born like that? Plenty things people ask me you know."*

Perceived stigma or self-stigma can cause mothers to think about what others may think about them and thus they can feel devalued (Ali, Hassiotis, Strydom & King, 2012), in the sense that they will feel blamed and guilty as a result of causing their children's disability. This can be compounded by religion and cultural beliefs which can negatively affect the psyche of mothers (Munyi, 2012; Kamenopoulou & Dukpa, 2018). Ana, for example, and as discussed earlier in the chapter, explained that as a Hindu follower, she was blamed for her child's disability. Prabha was stigmatized by others for not being able to make a *"good child"* and Sherma for most of her life hid her adult child from the public's eye by limiting her social interactions. Therefore, stigma and perceived stigma resulted in social isolation for the mothers and their disabled children in this study.

From a cultural point of view, Ana rightly pointed to the fact that no one was open and accepting about disability or even interested in finding out about her and any other mother's experiences or their children's disabling condition. In the Trinidad and Tobago cultural context and as a manager of an institution that caters to disabled children, I have first-hand experience in knowing that "normals" as Goffman (1963) said, referring to persons without a disability, are sometimes apprehensive to approach parents of disabled children to even talk to them or render assistance if needed. It is as if they do not wish to confront disability in any way for fear of feeling the "abject" (Harvey & Long, 2020) by being too close as if they would "catch it." They prefer to ignore it, as Ana mentioned, which only serves to perpetuate stigmatization of disabled persons. I think what is worse, is the attitude of others can be considered indifferent as Ana pointed out when she said that nobody even asks what is wrong. From my perspective, the indifference 'ordinary' people show towards disabled children or their caregivers can more or less compound the lack of care and the isolation felt by the mothers or for all disabled people in general. The cause for society's negative reaction to mothers is not quite known and maybe an area

that warrants further investigation in Trinidad and Tobago. Therefore, as the findings indicate in this research, social stigma had a negative impact on mothers' psychological health, making them averse to even approaching others for support.

Self-Blame and God's Will

Sherma was the only mother who accepted the cause of disability as being sent from God. Although this was accompanied by sorrow as did for the other two mothers, Sherma accepted her fate in life to care for her daughter. Sherma, however, was also the only mother who had other children who were also non-disabled. Therefore, one may assume she had a better life balance by having other children who functioned well in society which potentially made her caregiving burden easier. While literature is not available in Trinidad and Tobago on the topic of parents having non-disabled siblings versus an "only child" who is disabled, other research suggests that family support can ease the caregiving burden (Cantwell et al., 2015; Munyi, 2012). Sherma accepted God's Will; she said: "*not one day in my life God above listening to me, I never said, God how my child come so? I cannot recollect, I never sit back and say God what it is I did?*" It was clear, therefore, from Sherma's account that she did not perceive herself to be blamed for her daughter's disability. However, other discussions above showed conflicting beliefs from her other experiences.

From a more psychological perspective, I found that since Sherma had a more balanced life and a full career, it was probably more reassuring for her to accept her daughter's condition as God's Will. Adopting this stance could potentially ease the self-blame and distress a mother carries which may have a more positive impact on her mental wellbeing. Sherma also had other children who were considered highly educated by society's standards to counteract the effects of stigma and lack of social support. Therefore, it is possible that the degree of blame and guilt experienced by Sherma would not be as profoundly felt as was for Prabha and Ana. For instance, the data showed that Ana blamed herself for working too much, which she said, resulted in the lack of oxygen in her child's brains. Such is a heavy burden to carry, for although she blamed the work, in reality, Ana, I think, blamed herself as it was *her* choice to work that she said caused her son's illness.

Maternal responsibility in this study encompassed a range of important concepts that surround caring for a child with a disability in Trinidad and Tobago. In summarizing this theme, the findings indicated that mothers' perceptions of disability changed somewhat from a completely medicalized and charitable view to the view purported by the social model of disability. However, they still maintained remnants of the charitable model as they felt sorrow for their children. This remnant cannot be viewed in the same way as other people in society, particularly the way non-disabled persons view disabled children. As a mother myself, I identify with the participants' perspective of feeling sorrow for their children because of their heavy emotional attachment and maternal love (Kikuchi & Noriuchi, 2015). Moreover, it is the sorrow that, unlike the wider society, drives them to do positive things for their children's development. Hence, when I say that they still hold the charitable view, is not a criticism of their view of disability. Being helpless in a society that discriminates and does not afford equal life chances for their children makes one understand why mothers will still hold a partially charitable view of disability.

It is precisely this perception of wanting to help their children that the mothers extended themselves to the point where they identified with their children's disability as an extension of themselves (Pierce et al., 2003). From a psychological perspective, mothers tried to provide for all their children's needs, be their friends, create happy and joyous moments throughout their children's life, teach them at home, nurse them and protect them. They assumed these multiple intense roles amidst stigma, blame, discrimination, isolation, exclusion, and misunderstood beliefs about disability that devalue them and their children (Boshoff, Gibbs, Phillips, Wiles & Porter, 2016; Van Trigt, Kool & Schippers, 2016). Arising out of these complex and intense caregiving responsibilities is what accounted for these mothers' perception of being the most efficacious and the experts in caregiving for their disabled children. This expertise, however, came at a heavy psychological cost burden for these three mothers. In addressing research question two, I examined the findings of mothers' perceptions of their caregiving role. In the next section, I will focus on research question three.

4.5 Theme 3: The Value of Support Services

This section looks at research question three that examines the mothers' perceptions of the role of government in caring for and educating disabled children in Trinidad and Tobago. In addressing this research question I present the data as it relates to three areas that I categorized under the theme of social services to be analysed: formal schooling, social and infrastructural support, and legislation in Trinidad and Tobago.

4.5.1 The Value of Formal Schooling

The findings indicated that formal education was problematic for all three mothers in raising their children. Prabha described her plight with accessing formal public schooling for her child and the dilemma she faced in accessing transport and funding.

“From as soon as she [her] father died, I started sending she[her] to school. I used to go and spend the whole day in school. Then they send we [us] to a school in Point, but the Point school was \$500.00. So I couldn't afford to pay that. Then I went to get the public assistance. Well when I get [got] the public assistance, it just helps my travelling sometimes, because the money used to be [was] never enough. She used to go to school Cara Jeff school. Well in there, we used to stay in school... I used to stay the whole day. Then Kate did [the] Common Entrance Exam and she passed for a Junior Sec [Secondary School] but I couldn't afford the books and everything [else] so, she didn't go to that school”

Ana was very vocal and spoke at length on her experiences regarding formal education for her son as she highlighted the inaccessibility to equal education opportunities and the cost of services.

“We got turned away from all [schools] because nobody wanted the responsibility of a child who was prone to seizures. It was very disheartening. I guess, in this country mental and developmental disabilities are pushed behind a closed door because of the stigma. So to find a preschool for him we went to twenty-six different schools and they all turned us away. Then we heard about the Early Childhood Centre in [Central] ... and [attending there] he was getting into a socialization with the other kids...and teachers as well. I think the education system in Trinidad and Tobago is very academically driven, so then you get left out. He is nine right now but his speech is probably at a three-year-old. But from where he was to where he is now progress has been great.”

In talking about her hopes for the future, Ana further added:

“I would like to see the education system restructured to accommodate these children. In this private primary school, he now attends, the teacher isn't even trained in Special Education, but she simply has a love of children, she is very kind, she is very attentive to them, and because it's a small class, they get the

attention that they need, but at a cost financially to us. It's not cheap, and every term you have to pay the fees ... because you have no alternative for your child."

Sherma also explained her experience in schooling for her daughter:

"She went to the 'normal' school. She wrote the common entrance, she didn't pass. After I sent her to a special school. But it had nothing more. They took her and they told us we have to integrate her into the normal school, that was the system, back in those days. Then we put her in a paid Secondary School...but she didn't write any exam. And she stayed there for 3 years, after that we sent her to do computer, and drawing, with a teacher, tutoring her at home, a private tutor. We took her to Servol, where they teach there also, but we didn't have to pay for that and I had her father there, who was a teacher himself. He used to guide me"

4.5.2 Discussion On the Value of Formal Schooling

The findings revealed that mothers all wanted their children to have a formal education and they saw this as a prime responsibility of the government. In the previous section, I discussed how mothers took the burden of home-schooling using their limited knowledge and experience in the absence of formal structures available to cater to their children's special needs. As discussed in Chapter Two, the Trinidad and Tobago government has committed to national and international mandates to cater to the needs of all children in Trinidad and Tobago. However, it was noted that these commitments by the government were not met to the required standard (Charran, 2018; Seetahal and Charran, 2018; Conrad, 2006; Lavia, 2007) as suggested by UNICEF (2007), UNESCO (1994a; 2009b; UNESCO, 2007) and other international bodies. Additionally, existing policies still need to be updated (National Policy Document on Persons with Disabilities, 2018) to reflect a greater degree of inclusion for disabled persons regarding their rights and participation in Trinidad and Tobago. Ana, for example, felt it was the easy way out for the government to not address the inclusion issue when she suggested that *"they hide"* some disabled children from the public's eye because there are no services available for such children. While there are some existing educational services for disabled children, there are not enough. In Chapter Two, I presented research highlighting that the country has twelve special government schools to serve the needs of 3,302 disabled children (UNICEF, 2017). These figures were based on Trinidad and Tobago most recent 2011 country census report and to date, ten years later, the current figures are still unknown. While some children attended private schools, the number of existing schools is still insufficient to accommodate the disabled children population.

Apart from the student/school ratio, the country does not provide for specific types of disabilities such as severe cognitive delays. However, there are schools for the visually impaired and for the deaf in Trinidad and Tobago. All other disabilities such as Autism, Cerebral Palsy, Down Syndrome, Dravet Syndrome, and other types of developmental delays are usually grouped into one. Mothers, therefore, may be apprehensive to send their children to formal school if they perceive that the care for their children is not adequate. Sherma and Prabha had more opportunities to school their children. However, Ana, based on the severity of her son's condition, opted to not send her son to any of those special schools because of his particular disability. She eventually found a private primary school where she had to pay so she would have a greater presence and a closer relationship with the teachers. On the days he could not attend, Ana taught him at home. A mother like Ana, with a child suffering from comorbid conditions, can battle greater mental stress, as she realizes she is the sole person responsible for providing all the educational experiences for her child (Owusu, Enoch, Mprah & Vampere, 2018). The mothers in this study perceived the government as not prioritizing education for disabled children and, to some extent, viewed the government as having perpetuated the stigmatization of disabled children. As a result, they see their children as not having an equal chance of development or equal rights as other non-disabled children in the country.

Most parents when having a child will have future expectations (Landsman, 2005; Madi, Mandy & Aranda, 2019) for the child as they grow and develop including having an education and forming relationships (Clemalciar, 2010). Formal schooling serves an important function for the socialization of children, which is the inclusion resulting from social relations (Zvoleyko, Tatiana & Klimenko, 2016). This aspect of interaction is particularly important for disabled children as they are generally misunderstood which compounds the exclusion (Charran, 2018). Children being denied the opportunity of having friends and peers will be deprived of appropriate social behaviors (Colledge, 1949) or be unable to gain independence from their primary caregivers. As Ana pointed out, when her son started going to school, he had a routine, came to know other figures in authority, made friends, and learned to interact. These qualities to a large extent were lacking, given the experience of Prabha's and Sherma's daughters, although they were much older. From the interviews, I gathered that their only friend was their mothers. This scenario creates a greater burden on mothers' mental health as their time becomes

increasingly concentrated on their children even in adulthood. For Sherma, the burden would be more significant since her daughter, aged forty, remained at a twelve-year-old cognitive development level. For these reasons, socialisation is an essential function of the formal school system that should be afforded to the public, disabled children included, as it prepares the child to be socially competent (Kristeva, 2013) and has the potential to create an avenue for independent living thereby easing the care burden and psychological stress of mothers.

In addition, all the mothers indicated that the cost burden of education for their children was an important consideration. For special needs students, especially deaf children, transportation and its associated costs (Alhuzail & Levinger, 2018) is a factor that worried the mothers. Prabha explained how she stayed in school all day for years for her child to get an education or to learn to “read and write” as she described it. Considering the larger implications for this mother and her unique circumstances, not only would she spend her days waiting outside the school compound, but she also would not be a full and contributing citizen; she would not be able to participate in work and cannot lead a conventional social life like other mothers. Indeed, her sacrifices are insurmountable. Prabha related “*my daughter is all I have*”, while Sherma similarly explained that her daughter “*is what I live for*”, and Ana spoke about her son, claiming that “*no one and nothing else matters*”. Therefore, every bit of finance these mothers had was arranged, budgeted, and prioritized to provide for their children’s educational and medical needs. Such a situation generates more stress on mothers in having to provide financially for their disabled children (Ghazawy, Mohammed, Mahfouz & Abdelrehim, 2020) and can negatively affect the quality of life for both mothers and children.

4.5.3 *Education, Employment and Independent Living*

One of the values of education is the opportunity to become gainfully employed and one of the ways this can be done is through inclusive practices for all persons, particularly for disabled persons. In developing economies such as Trinidad and Tobago, inclusion is “a dream in progress” as Charran (2018, p. 103) stated. The findings from this study revealed that for two mothers, Ana and Prabha, employment remains a desire for their disabled children. Sherma did not express such hope because she had accepted that employment was not an option as her forty-year daughter’s developmental age would

not surpass the age of twelve. Ana, in referring to her son, said *“but I will like to get him to the point where he can take care of himself, he doesn’t need mummy and daddy and he can step out of the door, and say, okay, I’m going to work, even if it’s for \$5.00.”* Prabha also expressed her frustration at the discrimination felt regarding her daughter’s opportunities as well as other disabled children for work:

“Nobody don’t care about them and nobody don’t ‘look up’ on them, nobody doesn’t give them a job. When my daughter finish[ed] school, do you know how much application she sent out? Even to the bank right across the road she did send[an] application, and when in the interview they heard she can’t hear, [and] she can’t talk, then nowhere [did]she got a job.”

Prabha’s words echoed the economic model of disability referred to in Chapter Two, which asserts that a person’s disability is used to assess their capability to participate in paid work, thereby focusing on the disabling factors of impairment (Retief & Letšosa, 2018). For the mothers, education represented a chance for future development where their children can sustain a level of functional independence in a seemingly unkind world. Being involved in work and interacting with colleagues, authority figures, the ‘built environment’ (Jackson, 2018, p.1), systems, and processes also creates a more inclusive and accepting environment for disabled persons. Employment can also benefit young adults with disabilities as the concept of disability itself can be more easily understood and therefore create a greater degree of integration into the fabric of society for disabled persons.

Saleh and Bruyère (2018) underscores the importance of work and independence for disabled persons. They argued that work is an important aspect of life as it is a source of economic power, personal and social wellbeing and provides a degree of security for necessities in life. These authors also stated that work permits individuals to use their skills and abilities as a way to establish their social position in society. Seetahal and Charran, (2019) also confirmed that work is a basic human right, which as Saleh and Bruyère (2018) note is at the core of what makes us all human. Hence when both mothers and their children cannot work because of disability issues, it indicates the dehumanizing and unfair treatment that disabled children and their caregivers undergo.

The mothers in this study live amidst the Trinidad and Tobago society which does not satisfy fully to their children’s needs, even though “Education for All” (UNESCO,

2000) is an international mandate to which the government subscribed (Seetahal & Charran, 2019; Charran, 2018). Chelsea Charran (2018) a Trinidad and Tobago researcher, postulated that although research in special education is limited, there are official policy documents that suggest that the provision of special education services is a priority of the government of Trinidad and Tobago. However, this seems to be an elusive goal as there is an absence of legislation, limited investment in disability research, lack of empirical data on disabled persons, insufficient educational opportunities for disabled persons, and a lack of employment opportunities (Lavia, 2007; Charran, 2018; Seetahal & Charran, 2019; Economic Commission for Latin America and The Caribbean (ECLAC), 2018; UNESCO, 1994). Therefore, mothers' perception of the government's role is that they are the body that can "look up," to use Prabha's term, or address the needs of disabled children, because they have the resources and power to effect necessary social and economic changes that can help their children.

4.5.4 *The Importance of Social Support*

The findings of the data captured mothers' stories that revolved around the type of support they needed. Apart from education which I previously discussed, I isolated two other areas that relate to the findings; these are social support and legislation on which I will now focus. Prabha related her experiences with the lack of social support she had in caring for her child and the 'trouble' she had with having to do it alone.

"If I have to go somewhere, I have to go toilet, and anything I have to do, I have to tote this child with me. It was really, really hard. She couldn't communicate because how [as] she couldn't hear and couldn't talk[speak] she feels somebody go do she [will do her] something or, poison she [her] or something. So I never left that child with anybody, even in school, when we go to school, I used to stay in the morning, the teacher used to let me stay in the morning. I do without [underwear], without clothes, without food, beg people for a dollar and two dollars, to travel to reach South, for this child to go to school, to make herself somebody"

Ana also expressed her dissatisfaction with the inaccessibility of government services provided for disabled children and the apparent hopelessness a mother could feel.

"but it is difficult to find simple services like a hairdresser or dentist, much less educational services and medical services. Government services are geared towards the blind, you know, people with physical disabilities. They now starting to do government buildings with wheelchair access and stuff like that. There are a lot of places that people with physical disabilities can't get into."

Ana further explained as she spoke about her son's place in society indicating equal access and treatment:

“Inclusion to me, would mean that he has a place in this whole system, that he has a place in society, because in Trinidad, people with disabilities, physical and even more so mental disabilities, are treated differently, they’re left out, they’re shunned, they’re not included in activities. I know it’s unrealistic of me to want to shelter my child from that, but for me that’s my job. And a lot of parents, especially low income parents, who are not well educated won’t know where to turn. I think in Trinidad and Tobago, persons with disability, especially mental disabilities, are kept behind closed doors because, because there are no services available to help them progress. Society does not want to see them, so if we close the door we don’t have to deal with them.”

Sherma also shared her experiences relating to social support:

“It’s just myself and my husband, I never had no[any] support, but she [Val] gets some money from the government. But Mom [Sherma’s mother] not willing to help, she was never willing, so I did what I had to do. But if you don’t have a supportive husband, you ‘gone through’ [you are doomed.]. My husband supported me one hundred percent. I used to take her after I come from work which was six to seven in the evening. But I think, nowadays there are lots of things now on stream for parents with kids like my child. They have a lot more than when my child was born, and I think that is a good start. And every day we are getting more on board, probably the government not doing as fast as they should. But I think everybody is more academically inclined to get things going. But in my days there was nothing, nothing. They say self-praise is no praise, but, I find I did a lot of good things for my child.”

4.5.5 Discussion on the Importance of Social Support

Mothers’ perception of the government’s role in caring for and educating their disabled children is seen through the lens of providing support services. Enhanced services can be a form of social support. This can be done at the diagnosis level through medical training and early intervention. Support can also be mustered through increased government funding for disabled persons and disability research, sensitization and awareness (for families and the general public), and structural support such as increasing care services for disabled children and their caregivers.

From the data, the findings reveal that the mothers did not have sufficient care services for their disabled children to afford them the luxury of having time for themselves. For example, Prabha described her restrictions in having to care for her daughter when she was a young child, by being occupied twenty-four hours, seven days a week. Since her daughter had a communication impairment, Prabha explained the child would be afraid of staying with people because she felt someone would “poison her” if she were given something to eat. However, my perception is that it was Prabha who did

not trust anyone to feed her child as she had a communication disability where she could neither hear nor speak. Further, it seemed unrealistic that the child could have known what being “poisoned” was at such a young age (four years) given her impairments. This points to the fact that mothers may not trust people or institutions with their young children because of the lack of credibility in the services provided. As noted in Chapter Two, disabled children fall within the category of a vulnerable population and therefore require a greater degree of protection (Groce, Kett, Lang & Trani, 2011; Goff, 2016; Jahng, 2020). As previously discussed, the situation was similar with Ana who refused to let anyone else administer medication to her son. Here again, I will refer to the point previously made, where, despite the issue of trust, mothers may also think of themselves as the care experts for their disabled children.

The findings from the data suggested that mothers did not trust other people with their disabled children. As a result, leaving their children under the watch of others was almost non-existent. All three mothers indicated that there was a lack of care services in Trinidad and Tobago for disabled children, regardless of the type of disabilities they encountered. They also indicated that they felt society, including their own family members, neither understood nor took the time to understand their children and their disability. As a result, Prabha and Ana specifically both relied on their spouses who, as the findings suggested, were the only ones they trusted. Sherma, on the other hand, raised two other children on whom she could have relied to some extent to care for her disabled daughter. Therefore, one can understand Prabha’s fears of coping and the added burden she felt as her husband had died when her daughter was four years old. The notion of perceived support (Sipal & Sayin, 2013) as discussed in the literature was absent from Prabha’s psyche, resulting in overwhelming feelings that most likely added to her already psychological stress burden (Al-Kandari & Al-Qashan, 2010).

I discussed in Chapter Two also, the importance of family or other kinds of social support for mothers who parent disabled children. Ana explained she had no support from members of her family. She faced labelling and stigma, and some of her relatives felt that her son would “*grow out*” of his disability and did not care to learn about it. In other words, it was their way of getting rid of the *problem* by ignoring it, thereby objectifying the child and his disability, as if he were something *less of a human* (Landsman, 1998; Boshoff, et al., 2016; Van Trigt, Kool & Schippers, 2016; Goodley et al., 2014) or not

worthy or deserving of attention. Sherma said her own mother neither helped nor wanted to, care for her daughter. As I pointed out in the literature, grandparents, specifically grandmothers, can be a source of support to mothers of disabled children (Crettenden, Lam & Denson, 2018); in the absence of that support, the burden falls squarely on the shoulders of the mother.

The concluding point to this discussion is that family members do not support for two reasons; one is that they may not be fully aware of disability itself or the extent of the care burden of a mother of a disabled child, and secondly, the mothers themselves fear this lack of knowledge from others, rendering their trust in *outsiders* as limited. Additionally, mothers themselves may not know enough about the specific disability of their children, so they would probably prefer to be present for every moment in their children's lives. In this regard, Ferguson (2002) reminds us that "a family's interpretation of the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities" (p.124). This statement confirms the point that family members absorb the stigma from society as they belong to that society. Additionally, as mentioned previously in the first theme further above, the lack of medical support for mothers at the diagnosis stage accounted for the absence of direction in managing their disabled children, which mothers had to learn from experience (Gona et al., 2018). The overwhelming feelings mothers experienced suggested that early intervention is needed to assist them in their caregiving journey. Hence consideration can be given by the government to address this area of care for disabled children and their caregivers by enhanced education at the diagnosis stage as well as ongoing public sensitization which should include family members.

4.5.6 *Legislation as Social Support for Children with Disabilities*

Mothers did not explicitly state that the Trinidad and Tobago government should pass legislation for disabled persons or disabled children as a means of social support. However, there were comments in the interviews that suggested it was the responsibility of the government in providing equal opportunities and accessibility of service for disabled children. Ana, for example, in referring to the rights of her son stated: "*I think somebody who is not a politician should push it [disability concerns] forward, somebody with a passion as opposed to having a political agenda. I think Kris is entitled to what*

every other child gets and he doesn't get it." Prabha in her own way expressed a similar thought that "*none of them don't work on those children*" referring to politicians. Sherma also shared her experience, while alluding to some degree of evolution on disability focus, stating "*in my days, say thirty-five years ago, we had nothing for Val.*"

As discussed in Chapter Two in the literature, the Trinidad and Tobago government committed to several international and national mandates to make provisions equitably and sufficiently for all disabled persons. These provisions included legislation which are the laws made by the government and which by its nature can give a certain amount of protection to people. The mothers in this study expressed the view that enough is not being done by the government to provide equitably for their children. When Prabha shared that "no one looks upon *those* children", she indicated in her own way to the government that more needs to be done. She was referring specifically to disabled children who, upon reaching working age like her daughter, should be given equal employment opportunities, especially given the mothers' painstaking efforts in securing schooling for their disabled children. Seetahal and Charran (2019) also addressed the issue of employment in the Trinidad and Tobago context, aligning it to discriminatory and exclusionary practices towards disabled persons in Trinidad and Tobago.

The previous sections demonstrated that mothers felt a level of discrimination towards both them, and their children by not having access to services, education and employment. These occurrences, they implied, came as a result of the attached stigma they faced from the *normal* population (Goffman, 1963). From the conversation in the interviews, mothers also indicated that they did not know how to begin to navigate the world in confronting the diagnosis of their children. They further expressed disillusionment in their ongoing caregiving journey regarding stigma and blame, accessing educational and other support services as well as securing funding for their sick and/or disabled children. All these concerns offer some prescriptive direction on creating equal opportunities and rights, which is a direct remit of the government of Trinidad and Tobago.

In Chapter Two, I pointed out that the only piece of legislation for disabled persons in Trinidad and Tobago is the Equal Opportunities Act (EOA) of 2000 (National Policy on Persons with Disabilities, 2018). However, this document still reflects a level

of discrimination according to international mandates, as it specified in Section Fourteen, that the right to freedom from discrimination in employment does not apply to the employment of a person with a disability in certain circumstances. For instance, if a person with a disability cannot fulfill the job requirements, it may cause hardships or risks to the employer or other employees (Seetahal & Charran, 2019). Therefore, even this Act is not fully supportive or enabling for the disabled population. Details on legislation and mandates may not be known or apparent to the general public or disabled persons and their caregivers. However, for policymakers, such concerns should be addressed as it focuses on the issue of equality of opportunities for disabled persons in Trinidad and Tobago. Prabha, for instance, tried very hard to get her daughter a job and was ultimately unsuccessful. Furthermore, as discussed in the literature, although there is an existing disability policy in Trinidad and Tobago (National Policy on Persons with Disabilities, 2018), it is insufficient in addressing the insurmountable needs of the disabled population. The exclusion children face at schools or the lack of schooling, the great financial burden parents bear, especially low-income parents, and the social isolation lived by mothers, all need to be more forcefully addressed by the relevant authorities.

One mother, Ana, did not accept or apply for the grant allowed by the government for disabled children as the other two mothers had done. From the conversation held with her, she indicated the disgust she felt when people look at her son with pity and which she said was “*demoralizing*.” Therefore, it can be deduced that Ana felt the grant was an act of charity. I refer to the literature that says that there is still a pervading belief in the charity and medical model of disability (Retief & Letsosa, 2018; Oliver, 2013) in many societies including in Trinidad and Tobago. Earlier under the section that deals with the cause of disability, I also argued that mothers felt sorrow for their children by subscribing partially to the charity model of disability. Here I will distinguish that their perception has a different consequence from the way the government may subscribe to the charity model of disability. Whereas the mothers were motivated by their sorrow to enhance their children’s development, the government’s charitable view may further exacerbate the disabling factors thereby causing further discrimination. Hence this marks the difference in the perception of mothers’ role versus the government role in caring for disabled children. It is my view, therefore, even at the government level, this charitable view of disability is perpetuated and therefore enacted through its policies. The distribution of grants, which cannot begin to address the needs of long-term illnesses or severe

disabilities in children, can make some mothers disheartened and angry, refusing to go through the bureaucracy of *begging* for their children. Further, mothers may take the view that this “handout” is another factor that may relate to the dehumanization of their disabled children and that it may potentially carry the additional stigma of being on state welfare. In cases where there is abject poverty or severe financial pressures in families, a parent may have no choice but to apply for the grants or depend on charitable organizations. The fact that there is no legislation and an existing policy that does not adequately address the needs of disabled persons, serves to validate this supposed subscription to the charity model of disability. Improved legislation on disability, therefore, is a much-needed action by the government of Trinidad and Tobago. The legislation will address a range of considerations such as equal accessibility, equal opportunities, marginalization, misguided perceptions about disability, social exclusion, and isolation for both children and adults. In the final analysis, legislation can serve to enhance the understanding or at least reduce the misconceptions surrounding disability.

4.6 Chapter Summary

In this chapter, I discussed extensively the findings in relation to the literature reviewed in Chapter Two as well as the research questions and themes generated from the interview data. From the findings and the analysis, one can conclude that mothers who parent disabled children have a unique set of experiences. They circumnavigate the difficult world of disability by being a non-disabled parent with a disabled child. The mothers had to understand disability or relearn the meaning of disability through their children’s illness and disabling factors. Their unique experiences are further compounded by having to find happiness with and for their children despite being given the unexpected news of a disability diagnosis. The mothers in this study traversed their complex circumstances without “an ounce” of preparation for their unexpected journey while mourning the loss of the “perfect” and “imagined” child (Landsman, 2005).

Apart from having these unique experiences, the difference with these mothers is that they have had to assume intense parenting roles that is different from the ordinary mothers (Woodgate et al., 2015). Living in a society such as Trinidad and Tobago that caters little for their children’s particular needs, these mothers had to assume multiple roles and be the lifelong protector for their children. The psychological impact, therefore,

on assuming these multifaceted roles (Tsai, Tsai & Shyu, 2008) can have a potentially negative impact on mothers' mental wellbeing. Their restrictions manifested themselves by severely limiting mothers' participation in work, social interactions, leisure, or self-development activities and even curbing their desire or need to have other children. Research shows that mothers who parent disabled children, therefore, absorb their children's disability as their own (Landsman, 2006) thereby creating a new self-identity as that of their disabled children (Lalvani, 2011).

Such an identity carries with it the heavy burden of stigma and labels. Mothers bear these burdens for both themselves and their children and at the same time try to fight for the rights and recognition of their children as worthy human beings (Landsman, 2005). The mothers in this research struggled with the battle of being their children's voice, their body, and mind while simultaneously trying to prepare them for a future life where they could live independently after the mothers' demise. Relinquishing this ownership of their children poses another conflicting problem as they see their death mirrored in their children's lives while they hoped that this "extended self" (Pierce et al., 2003) would survive. They live with the hope that the greater good can be done through the government's intervention where they hoped one day all disabled children can live equitably and free from discrimination like non-disabled children in Trinidad and Tobago.

As I conclude this chapter, I ponder on the fourth research question which enquires into the lessons learned from mothers' perceptions and the significance of accessing the deeply personal and social experiences of the mothers in this study. This concern will be addressed in the following concluding Chapter.

5 Chapter Five - Conclusion and Recommendations

5.1 Introduction

In the previous Chapters, I presented the background and setting of the research together with the participants' experiences and perceptions in raising a disabled child in Trinidad and Tobago. In this chapter, I will present the conclusions and recommendations of this thesis by answering the research questions and reflecting on several headings namely: a) a summary and aims and objectives of the research; b) a synopsis of the main findings; c) potential strengths and limitations of the study; d) possible contributions to knowledge; e) recommendations for future research; f) personal reflection on my doctoral journey, and g) final comments.

Research Aims and Objectives

In this study, my primary aim was to gain and share a comprehensive understanding of the perceptions and the unique lived experiences of three mothers who parent a disabled child in Trinidad and Tobago. The way mothers construed the meaning of their daily lives was important as it provided an understanding of how they navigated both the negative and positive realities of the disability experience in this country. Therefore, an objective was to uncover their perceptions of their role as the main caregiver of their disabled children. As they spoke of their myriad roles, I also sought to unearth the mothers' perception of the role of the Trinidad and Tobago government in relation to providing educational, care, and support services for disabled children. And finally, I aimed to understand how the knowledge gained from mothers' perspectives of their caregiving experiences can assist in improving the quality of life for mothers of disabled children and by extension, all disabled persons in Trinidad and Tobago.

In this dissertation, I used a qualitative approach to this inquiry as I wanted to extend my understanding of the lived experiences of mothers who parent disabled children. I felt narrative inquiry was the most appropriate approach for this study as the nature of experience is unique for each person and therefore must be interpreted and analysed according to its particular context (Clandinin & Connelly, 2000) and with people in their natural settings (Denzin & Lincoln, 2011). To carry out this investigation, I used

personal in-depth and unstructured interviews as the main primary data collecting procedure by recording and transcribing the verbatim from participants. Thematic analysis was used to uncover salient points that emerged from the data. I used a few guided questions as well as my own supplementary notes to capture participants' immediate reactions in recounting their stories.

This particular research paradigm proved to be effective since my thesis is a study of experiences and the storied lives of mothers. Mothers told their stories willingly and shared very personal thoughts about their caregiving journey, sometimes revealing sensitive information about themselves, their families, and their lives. In so doing they have contributed to the answers to the research questions which overall, sought to provide a better understanding of mothering disabled children in Trinidad and Tobago. The information gleaned provided insights into a) how mothers perceived their caregiving role, b) the psychological aspect of their care burden, c) daily life challenges, d) the impact of little social support and, e) the need for government to become more involved in educating and supporting disabled children and their caregivers. Overall, this study has achieved its aims and the central objective which was to provide literature on understanding disability from the perspective of a mother residing in the developing country of Trinidad and Tobago. Generally, the findings proved that the mothers experience an extensive psychological burden in mothering disabled children in Trinidad and Tobago.

The Research Questions

In this chapter, I present a synthesis of the main findings to research questions one, two, and three, while in the fourth research question I offer consolidated takeaways from the conclusions of the preceding three research questions.

5.2 The Value and Relevance of Understanding Mothers' Experiences

Research Question One: *What is the value and relevance of understanding the lived experiences of mothers parenting disabled children in Trinidad and Tobago?*

The lived experiences of mothers caring for and educating their disabled children in Trinidad and Tobago comprised both personal and social experiences. The findings

indicated that mothers underwent a unique set of experiences in their caregiving journey. This uniqueness manifests itself in the specific psychological processes intrinsic to the primary caretaker's experience (Hassan et al., 2021). I pinpointed three specific areas which brought the unique maternal experiences into focus: unpreparedness, expectations of the normal and, mothers finding happiness with their children despite the difficulties in mothering disabled children. At diagnosis, I found that mothers experienced a great deal of trauma in receiving the news of their children. This trauma resulted from the unpreparedness they encountered from the unexpectedness of the news. Additionally, the literature confirmed that they experienced mental stress from the loss of the desired or imagined child (Barbosa, Chaud & Gomes, 2008). Such trauma was not just a passing moment at the point of diagnosis but lasted for a long time or maybe it will always be situated in mothers' psyche as they may have questioned themselves for being a potential cause of their children's disability. Their unpreparedness also led to anxiety in determining how to imagine the future in caring for their children. They had to consider altering their lives as they could not foresee what the development trajectory of their children will entail. Hence the uniqueness of their experiences was in the adjustment of their expectations (Barbosa et al., 2008) and having to learn to accept their *abnormal* children. After these trying times for mothers, their experiences also showed how they found happiness with their children and learned to live through their journey making unusual sacrifices that mothers of non-disabled children do not have to typically undergo (Al Sayed, Alaskar, & Alonazi, 2020).

Through an exploration of their experiences, and an understanding of the burdensome psychological processes mothers of disabled children endure, various persons in society namely the government, the family of disabled persons, and mothers of disabled children themselves can gain a deeper understanding and appreciation for the realities of these mothers. Optimistically, this understanding will lead to providing support to mothers and ultimately to their children.

5.3 *Mother's Perception of Their Caregiving Roles*

Research Question Two: *How do mothers perceive their roles in caring for disabled children in Trinidad and Tobago?*

In this thesis, I addressed this research question twofold by firstly examining the perceptions of mothers towards disability, followed by how they perceived their roles in caring for their disabled children. To understand mothers' perceptions of their roles I found it worthwhile and relevant to know how they conceived of disability regarding attitudes and treatments towards children and adults with disabilities in Trinidad and Tobago. The data showed that there were times when they subscribed to a charitable perspective of disability. In one way, they held pity for their children and other disabled persons in Trinidad and Tobago, thus alluding to the charity model of disability (Retief & Letsosa, 2018). Another view is that at the point of diagnosis they felt that their children's disability could have been cured or helped if the correct diagnosis and treatment were given by medical experts, thus justifying the medical model of disability (Landsman, 2005; Singh & Chopra, 2020). They also held notions that society was responsible in part, for creating a disabling environment and restricting the development of their children, thereby implying an affiliation to the social model of disability (Oliver, 2013; Jackson, 2018).

My view is that having a child with a disability influenced mothers' perceptions to the extent that they held a broader perspective on disabled persons in general. Their preconceived notions changed from the predominantly sympathetic view to the recognition of the value of the human experience in general, and specifically, to see their children as having lives worth living (Landsman, 1998; Goodley & Trekgaskis, 2006). In other words, their perceptions "evolved" (WHO, 2011) although there were still remnants of the charity aspects of disability. The mother's perceptions and expectations of others also evolved based on the length of time they lived with the child's disability. As I maintained in Chapter Four, the older the mother became and the longer they lived with the disability of their children, the more accepting they became of their realities with possibly a more tolerant outlook to life regarding living with their disabled children in Trinidad and Tobago. As the social constructivist theory purports, realities are inter-subjective and can change with experience. The mothers in this regard would have changed perceptions of self because of the diversity of their experiences relative to society (Crisp, 2002), as it concerns living with their disabled children.

In addressing the issue of how they perceived their roles as the main caregiver and nurturer of the disabled children, the mothers assumed multifaceted roles such as educator, nurse, financier, and advocate. Despite the stigmatizing challenges mothers

faced, and the heavy psychological burden they experienced in raising their children, the mothers exhibited a notable degree of resilience in coping with their struggles. It is my view that the notion of ownership as discussed in Chapters Two and Four, was so strong that it surpassed their desire to blame anyone else for their children's condition. This sense of ownership allowed mothers to perceive themselves as ultimately responsible for caring for their children both in life and in death and as a result, carried feelings of self-blame (Brown, 2013; Tsai, Tsai & Shyu, 2008). Despite the lack of social support, care services, resources, and funding, the mothers viewed themselves as the most efficacious and competent in carrying out their roles. The presence of their undying maternal love (Kikuchi & Noriuchi, 2015) allowed mothers to prepare themselves for this intense, life-long journey, becoming the experts by their self-taught life experiences in raising their children whose lives, to them, were more than or just as valuable as their own.

5.4 Mothers Perception of Government's Role

Research Question Three: *How do mothers perceive the government's role in providing educational and support services for disabled children in Trinidad and Tobago?*

Although the mothers felt they were the most competent and responsible for their children, they still saw the need for government to act in the interest of all disabled children in their country. They did not specifically speak about the government's role concerning their children only but generalized to all children and persons living with disabilities in Trinidad and Tobago. It was their view that the government was the only entity with the necessary resources, money, and power to effect social changes which could directly benefit their children.

One particular area where mothers felt the government had an essential and critical role was in the provision of formal schooling to disabled children. They directly specified that their children could and would have benefited more from the public education system if measures were in place to address the needs of their children's specific disabilities. They also felt that schools could foster a degree of inclusion and accessibility to formal structures that they cannot provide. Additionally, formal schooling would provide socializing opportunities which is an important component of learning and development for their children (Zvoleyko, Kalashnikova & Klimenko, 2016). Exposure to other persons in school may also help to reduce the stigma and increase the

understanding of disability as it involves a greater degree of social interactions. Hence, mothers were of the consensus that the government's role was crucial in providing equitable access to quality education. They saw this as an added advantage of their disabled children having an equal chance for independent living. The mothers expressed that although they homeschooled their children to the best of their abilities, the government was ultimately responsible for formal schooling. Schooling will also ease the burden of mothers as it will bring a greater life balance and give them more time to engage in activities like other typical mothers in society.

With reference to legislation, the mothers felt that more could be done by the government in providing social support services for disabled children. Social support services include care services that are not readily available for disabled children and those that are available are very expensive. The findings showed that the mothers thought the government had the power to ensure that all children receive equal access to educational and other services as well as equal rights as other children. However, the mothers saw the government as neither fulfilling their role nor dismantling the barriers to inclusion. It is indicative from the findings that if disabled children were granted equality of opportunities, the mothers' care burden would be alleviated and their peace of mind regarding the future life and survival of their children as well as employment opportunities would be more attainable. Overall, I support Mack's (2014) view that legislation would provide for enhanced social and financial support, empower caregivers, build awareness about disability, reduce stigma and provide for equality of opportunities for all children and adults with disabilities in Trinidad and Tobago.

5.5 Insights From Experiences and Perceptions

Research Question Four: *What lessons can be learned from mothers' perceptions and experiences in raising disabled children in Trinidad and Tobago?*

Through a synopsis of the findings from the other three research questions, the following can be said about the lessons learned:

1. To not understand the value of the uniqueness of mothers' experiences is to almost deliberately ignore the realities, both hardships and happy moments of mothers of disabled children and disabled persons themselves. This disregard or what may

be considered indifference is what I think devalues disabled people. It indicates an absence of recognition of the work and multiple roles mothers assume for their disabled children. As a consequence, this invisibility of the lives of both mothers and their disabled children compounds the stigmatization and isolation of this group in society.

2. Mothers held different perspectives on disability which were coloured by their personal and cultural beliefs. Had the mothers solely followed the charitable and medical models, they would probably have acted differently in sourcing help or equal and fair treatment for their disabled children. However, they had notions of both the social and bio-psycho-social model of disability which supports the functioning aspect of disabled persons (WHO, 2011). Such a shift in perspective indicates that they adopted a more progressive stance as they felt empowered to seek different avenues to help their children function and live independently. In other ways, changing a view from a strictly charitable one to a broader understanding of disability can work in the favour of their children's development. In a broader sense, society itself can learn to change its perceptions if it internalises the mothers' understandings as the findings of this thesis have demonstrated. Mothers therefore now view society, including themselves, as having a bigger part to play with shared responsibility for disabled children (Beizer, 2002) thus giving both mothers and children greater visibility where mothers could advocate for their children.

Despite the mothers' beliefs about disability, however, the mothers saw themselves as the owners of their children, and the ones ultimately responsible, efficacious, and competent. From the findings, it is evident that mothers will continue to feel this sense of responsibility for the rest of their lives. Mothers' determination combined with positive actions by the government in terms of legislation and social support could signal a collective responsibility for optimally caring and educating disabled children in Trinidad and Tobago.

5.6 The Limitations of the Study

The limitation of this study lies in the number of participants and the limited cross-section or representation of the population. As discussed in Chapter Three this study had three participants. I made several attempts to contact other potential participants, who

verbally agreed to be involved but eventually, never responded positively. It would be interesting and noteworthy to find out why those mothers were not forthcoming to share their stories. The limited number of participants in this research cannot fully represent the diversity of mothers in Trinidad and Tobago. Furthermore, all the participants who agreed to be interviewed were of East Indian descent, like me. Therefore, the results would have been culturally skewed as other ethnicities were not represented. Additionally, the three participants represented the lower to middle-income bracket. None of the participants belonged to the upper socio-economic or wealthy group of citizens. As mentioned in Chapter One, Trinidad has a diverse cultural heritage with the main races comprising African and Indian ethnicities (Central Statistical Office, 2011). However, although I contacted several persons from African and Chinese backgrounds for participation in this research, they all refused to be involved. I mused over the reasons why no other ethnicity agreed to participate in my study and wondered whether there was an issue of trust or some other reason. However, this may be an area of research that needs further investigation. Notwithstanding this, I do believe that a more diverse representation would have provided different findings and results in understanding the perceptions of mothers parenting disabled children in Trinidad and Tobago.

While this research sought to investigate the perceptions and experiences of mothers parenting children with a disability, another limitation is that I did not focus on any specific type of disability. The findings and analysis proved that depending on the type and severity of the disability with which mothers had to contend, their experiences differed in various ways. Additionally, the findings disclosed that the age and stage of development of disabled children could show different results regarding the caregivers' mental and emotional wellbeing. As this study investigated mothering any disability, a comprehensive analysis on each particular disability could not be fully accomplished. Furthermore, as mentioned in Chapter Four, I found that the length of time a mother lived with her child's disability influenced how she perceived disability as well as the expectation she held of others in society. This research, however, did not set out to investigate the age of mothers and the specific period during which they were caring for their disabled children, but indications of the same did emerge from the data.

A further limitation I felt was regarding my position as an insider /outsider researcher. Although the positive outcome of being in the insider position was that the

mothers had a degree of trust in me because they knew me to a certain extent, I felt that the information they provided vied on the side of caution. That is, they only trusted me up to a certain point and therefore were careful in divulging unpleasant or adverse feelings they may have had towards their children. Hence, I think they maintained the role of protector for their disabled children even throughout the interview process. Given the context of Trinidad and Tobago and the stigmatizing beliefs the disabled community endures, (Mack, 2014) and given the time limitation I had for completing this thesis, I felt that had I conducted more than one or two interviews and built a rapport with these mothers over time, there would have been greater detail in the information provided in the interviews. I am optimistic that over a longer duration, or after three interviews at least, they would have gotten to know me better and therefore trust me even further. Therefore, I feel that establishing a relationship with persons to be interviewed for personal stories is something that one should do first before formally engaging in qualitative interviewing. Hence, I feel that the experiences and perceptions shared by the mothers had the potential to limit the quality and quantity of information given for this research.

In relation to the idea of trust, a possible limitation is the subjective nature of my interpretations. Since qualitative inquiry is based on assumptions where a researcher's position is 'coloured by values and beliefs' (Sikes, 2004, p.18), both researcher and participants can be influenced by several factors such as religion, beliefs, ethnicity, social class, race, history, and culture (Denzin & Lincoln, 2011). I, therefore, acknowledge that as a mother and an outsider researcher, my perceptions and experiences about raising a child with a disability would have influenced my interpretations.

Another limitation was the lacuna of empirical literature in the Caribbean and particularly in Trinidad and Tobago on the topic of mothers' experiences in parenting disabled children in Trinidad and Tobago. There was research available on disability in Trinidad and Tobago, but most had a focus either on disability regarding teacher education, inclusive education, poverty, and disability, or employment and disability (Lavia, 2007; Seetahal & Charran, 2018; Conrad et al., 2010). Hence there was no research focusing specifically on the experiences of mothers. This is precisely why I feel my study is critical to understanding disability from a mothers' perspective in Trinidad

and Tobago, the Caribbean generally and beyond, as it gives visibility to mothers and their plight in nurturing their disabled children.

5.7 The Strength and Contribution of My Research

The strength of my research is found in the topic itself. To the best of my knowledge and as stated before, this topic has not been explored in Trinidad and Tobago this seminal study presents first-hand data and detailed analysis about mothers' perceptions of their role in raising disabled children in this country. My study brings an original contribution to the knowledge base on disability in Trinidad and Tobago. To further promote the accessibility to the information provided in this research, I plan to make my thesis available for local libraries and universities so that educators, researchers, and policy-makers can use it where appropriate. I also plan to upload this dissertation to the White Rose Online E-Thesis Repository for further accessibility.

Another strength is that the methodology and methods I adopted were of significance as they allowed me the chance to gather thick, rich descriptions (Geertz, 1973) of participant lives that other methods, such as quantitative inquiry would not have provided (Patton, 2002). Using the interpretivist paradigm, I have provided an explanation of the infused perceptions of the participants regarding social interactions with their interpretation of cultural norms to derive meaning (Hengst, Devanga & Mosier, 2015) from their daily lives in their disability experiences. Therefore, the method I applied in articulating the data collection and the resulting comprehensive analysis is another strength that demonstrates the attention I paid to the details of participants' stories and of which I employed all the ethical considerations while conducting the research.

5.8 Further Research

As highlighted in the sections above and previous Chapters, there is generally a greater need for further research in disability studies in Trinidad and Tobago. First, I believe research into the effects on mothers' psychological well-being on having children with specific disabilities should be investigated. This will give a clear indication of the type of intervention services needed to assist mothers. Many local writers (Lavia, 2007; Conrad et al., 2010; Mack, 2014; Charran, 2018) have indicated the need for enhanced

educational service and investment into disability, although none looked specifically at mothers' perceptions with their special needs children.

Secondly, future research should focus on the effects on mothers' mental well-being in Trinidad and Tobago in receiving the diagnosis of a disability of their children so appropriate systems can be developed or implemented to assist them in the start of their intense parenting journey (Woodgate et al., 2015). As the findings indicated, none of the mothers had any knowledge of treating with such unexpected news which posed a great degree of trauma on their mental wellbeing. The literature has also confirmed that diagnosis is an area of concern regarding mothers' health and wellbeing (Landsman, 2005; Graungaard & Skov, 2006).

Thirdly, as the study found, there is a knowledge gap in how mothers think, feel or treat children after living with the disability for several years. All participants in this study had a different disposition depending on the age of their children and their own age and stage in life. Such information can be useful tools for developing programs that will encourage independent living for disabled children as they grow into adulthood. Independent living can afford young adults a chance to live as any other human being with dignity, and autonomy, raising a family, working, volunteering and participating in civic duties. Equality of opportunities not only encourages disabled children to be valuable contributing citizens, but more significantly, it would ease the mental strain on the mothers in worrying about what will happen to their children if their children outlive them.

Fourthly, there is a need for more literature on the experiences of mothers caring, and educating children with specific types of disability or comorbid conditions. This study found that the intensity of the parenting roles varied depending on the type of disability mothers had to cope with in their children. Therefore, researching this area will provide added information for policymakers on how to help mothers manage their children who are simultaneously sick and disabled or severely disabled.

Fifthly, another area that may be considered for future research is the way mothers of different ethnicities treat with or manage their children's disability and the impact of culture on their caregiving experiences. Do mothers of African, Chinese, or Caucasian

descent have greater support? Are their communities or families more sensitive to their caregiving burden or are they more vocal regarding their children's rights? I have only investigated mothers of East Indian descent, therefore, enquiring into the perceptions of other mothers in Trinidad and Tobago or doing a comparative study can be a consideration in gathering additional information about disability in Trinidad and Tobago. Further research can also factor in the socio-economic status of mothers in parenting disabled children, to understand whether, from a psychological perspective, their financial status or affordability could offer a greater life balance.

Finally, research in Trinidad and Tobago should focus on the long-term effects on families and caregivers when young adults with disabilities cannot find employment and have to remain under the care of their parents or have to constantly depend on state welfare. This can create almost perpetual anxiety on caregivers as this study has shown. The mothers in this study often envisaged dying and death of both their children and themselves, fearing for the future survival of their disabled children.

The areas for future research highlighted in this section can provide valuable information if explored and will add to the understudied topic of disability in Trinidad and Tobago as well as provide broader insights into the mothering experiences of disabled children.

5.9 The Implications of My Findings

In the previous section, I looked at exploring future studies on understanding disability in Trinidad and Tobago. In this section, I will reflect on the implications of my research for academia on disability, legislation and government policies in caring for and educating disabled children in Trinidad and Tobago and the psychological impact of the caregiving experience.

In Chapters One and Two, I discussed the history and background of Trinidad and Tobago and the context of disability development over the years. Education and care for disabled children had humanitarian and charitable beginnings which then moved towards a rights-based paradigm (Conrad et al., 2010). There is evidence in the literature to prove that there have been strides in the right direction for inclusive education in Trinidad and

Tobago (Mack, 2014). However, my research has demonstrated that progression in this domain by the country's government has been lethargic, in that disabled children are still left behind, for example, their inability to compete with the examination-driven education system (Lavia, 2007). Although the move to inclusive education has been spoken and written about (Lavia, 2007; Conrad, et al., 2010. Mack, 2014) it is not a lived reality for many disabled children and their parents. Therefore, this research has demonstrated that parents still feel that more can be done by the government to increase accessibility for disabled children in the formal education system more holistically and equitably.

The results of the findings indicate that there is a need for legislation directly related to equity for the treatment of disabled persons, not only in education but in other areas as well. For example, there is a need for government to encourage and promote paid employment of children reaching the age of employment. Implicit from the findings of this study is that government needs to provide avenues where mothers can access other essential services for disabled children, such as sporting activities, personal care services, and financial assistance. Although some policies exist by way of grants (MSDFS, 2017), these policies still need to be reviewed to reflect a more stringent approach to equal treatment for all disabled persons. Childcare for disabled children is also expensive and burdensome. As found in this study, mothers had to give up paid work to care for their disabled children. Such a situation can lead to welfare dependency from the state (Parish et al., 2010). Government should consider this situation for mothers especially single mothers whose burden could be excessive, rendering them unable to cope, unable to work, and therefore unable to afford optimal childcare services, which in the final analysis put disabled children's development at risk. Therefore, updated legislation is needed in all areas with a focus on inclusion, education, care services, employment, and financial aid for disabled children. An added benefit of legislation is that it creates visibility for all disabled persons and their caregivers which can potentially lessen the stigma associated with children as well as adults with disabilities.

5.9.1 Implication for Schooling

The findings revealed that it takes a long time to understand and manage the behaviour of disabled children which could carry implications for educators. Further, mothers can be sceptical of placing their disabled children under the care of educators

who they feel may not be adequately trained, as this study's findings showed. Therefore, if mothers are more involved in the schooling of their children, they would feel a greater sense of comfort and less worry and possibly enjoy a greater degree of social involvement and participation. In this regard, my research can inform teachers on the benefits of partnering with mothers so that a more nuanced understanding of disabled children can be gleaned. A workable partnership can encourage mothers to reinforce what is taught in the formal school system, thereby providing an avenue to assist them to manage and teach their children at home. Similarly, teachers can also learn from mothers about how to deal with children and their unique behaviours in the classroom. This can be especially helpful for the disabled children who have difficulties in communicating, given that most children with mental and cognitive disabilities are usually placed in one classroom in Trinidad and Tobago. I believe that such a partnership would have a positive impact on mothers' mental wellbeing as well as an enhanced development of the disabled children.

5.9.2 Implication for Mothers

This research found that mothers had a strong sense of ownership for their children. Generally, parents expect their children, to live an independent life as they grow older. The mothers in this study all expressed the hope that their children would one day take pride in their self-development and be able to care for themselves. They expressed pride and joy in their children's development and wished they would live a 'normal' life, but yet the data showed the mothers' possessiveness over their children. Hence, my study can illuminate for mothers this unconscious sense of ownership that can potentially restrict their children's development and further add to their caretaking burden which could also cause them to become self-isolated. Therefore, knowing about the degree of their possessiveness can help mothers realize that they may need to seek psychological help or source other types of support.

5.9.3 Implication to Theory

I highlighted the strength of my study above in a previous section referring to the contribution to the literature. However, I felt that one of the implications of this study is the need to contribute to the body of literature that has not fully explored the notion of ownership. Further exploration of this fairly new concept may lead to a greater understanding of how mothers perceived their role in caring for their disabled children

(Jeske, 1996). As pointed out in Chapters Two and Four, there was only one article by Jeske that specifically focused on the topic of ownership the way my study examined. This topic can lend information into the psychological nature of mothers' treatment of their children, for both adopted (Beizer, 2002) or birth mothers, the way others can understand mothers' experiences, and the assistance that can be given to them.

Similarly, I felt that there is merit in further exploring the intersection of charity and disability from the caregiver perspective. While this research focused on Trinidad and Tobago, I feel that as a contribution to the literature generally, a critical exploration of perceptions of charity can have other implications on how we can further understand disability and its associated perceptions. In this thesis, I explored how mothers held the notion of charity and sorrow for children. I also feel the "selfish" notion of power is closely associated with feeling sorry and "doing good" for persons with a disability. One may ask: Is this what disabled people want - sympathy and charity? My feeling is that the answer will be a resounding "no". The disabled may certainly benefit from assistance, but in a way that they can promote their independence and dignity, where they will not be perpetually reliant on state welfare or family support. In this study, I have shown that the mothers also want these benefits for their children as they grow into adulthood. I feel a critical exploration of the concept of charity can lend further insights into understanding disability from the perspective of the interplay between charity and power.

5.10 Recommendations

In addition to the insights given above, I present here some suggestions that may be useful in addressing caring for and educating disabled children in Trinidad and Tobago:

1. Schools should establish a workable partnership with mothers of disabled children and teachers. I believe this will assist in understanding children and their specific disabilities which in the long run will ease the burden of both teachers and mothers. As this study focused on mothers' journey, it showed that mothers usually are the ones who adopts the role of educator, where they try to home school their children. Hence a partnership with teachers can work in the favour of both teachers and parents.

2. There should be an early intervention consideration for mothers at the point of diagnosis. The government through its health education sector should ensure the availability of trained personnel to educate parents on the disability of their child and provide follow-up services and support for mothers to assist them on how to manage their children going forward after diagnosis.
3. There should be aggressive attempts by the government to build societal awareness through public education and social media, of disability in general and specifically for disabled children so that the stigma at the school level as well as at the public level can be reduced or eliminated. The government should also consider greater investment into funding research on disability as this can also build awareness.
4. The Trinidad and Tobago government should consider enacting legislation and establishing or updating policies that will afford disabled children an equal opportunity for schooling as well as other care services that will enable mothers to optimally care for their children. Government should also legislate to reflect equal opportunities for employment for disabled persons, in both the private and public sectors as well as fulfill its international mandates to provide services for all disabled persons in Trinidad and Tobago. Legislation speaks to capacity building and is indicative of societal growth and can only be accomplished by political will (Mack, 2014). Adherence to the bio-psycho-social model of disability purported by the WHO (2011) may assist the government in changing its own approach to treating disabled persons in Trinidad and Tobago.
5. Non-Governmental Organizations (NGOs) and Community Based Organizations (CBOs) and Faith-Based Organizations (FBOs) and other affiliated disability groups in society should, through outreach programs, encourage forums where mothers can come together and advocate for their disabled children in a more organized manner. This can also be an avenue for mothers to receive information about disability as well as encourage them to be a support group for one another as mothers or caregivers of disabled children. It may also represent a form of pressure for the government to act in the interest of all disabled persons.

5.11 Personal Reflections on my EdD Journey

I would like to take the opportunity to reflect on my doctoral journey as a qualitative researcher. Pursuing this doctoral study has been an experience that will impact me for the rest of my life. I had no prior experience in conducting a narrative inquiry. By conducting in-depth interviews and being involved so intimately with other people's lives provided me with a great deal of insight into the process of research. I realised the value of qualitative inquiry and the difficulty associated with it in analysing people's experiences. I believe I have more confidence in my ability to undertake other research having gone through this rigorous process.

Additionally, I acquired valuable knowledge about how to be open-minded and independent in my role as an insider/outsider researcher. I appreciated the participants' involvement in this research and despite my own perceptions, I had to look critically at the data and be as objective as possible while still recognizing that my interpretations will always be subjective. The topic of study was also a learning point for me as I developed an appreciation for the literature on disability which extended my knowledge in this area tremendously. I experienced many difficulties securing the exact focus of the study through my research questions as I had to refine my research question many times. Another learning experience for me was doing the Methodology and Literature Review Chapters several times. The number of iterations I did and redid was at times depressing and made me doubtful of my ability to finish. However, they brought clearly into focus the reason why I was doing this study as well as understanding how to do it. Reading the book on Narrative Inquiry by Clandinin and Connelly (2000) and a chapter on methodology by Pat Sikes (2004) were works of literature that illuminated the nature of qualitative inquiry and contributed much to my understanding of qualitative research. My data analysis chapter revealed insights into mothering disabled children in ways I could never have fathomed. The chapter provided me with the opportunity to critically evaluate many aspects of a mother's life and the value associated with knowing and finding about the disability experience. It left me with a thirst to find out more about persons who live with a disability not only in Trinidad and Tobago but generally anywhere in the world.

Interviews with my participants left an indelible mark on the significance of conducting research and collecting data. Getting an interview with the participants was an invitation to be a part of their lives, something, I believe, is synonymous with a

precious gift that no researcher should ever take for granted. I now understand why so many mothers I approached refused to participate in this research. Opening a door (literally and figuratively) for a researcher to enter the lives of their fragile children, whom they guard with their lives, is not something any or every mother in Trinidad and Tobago would be willing to do. For this reason, I have utmost respect and appreciation for the participants and their contribution to knowledge by sharing their experiences for this research. I learned to appreciate the importance of my participants' perceptions and experiences and tried to represent them as honestly and accurately as possible. I have had to unlearn certain preconceptions I had about disability. For example, I thought all mothers had an awfully difficult time *all the time* in parenting their disabled children. Now I know they enjoy their children as much as I do mine.

I must admit, giving up doing this thesis was a thought that entered my mind more than once. The journey was an arduous one. I had serious issues with writing. Apart from some health concerns, I also had issues with being a mother and like my participants, had to be there for my children as well. I questioned why I decided to engage in this course of study and whether the perceived benefits were worth the actual stress. One of the things that I came to regard more than anything is the value of good support. My supervisors were extremely supportive and acted as a great source of motivation that brought me to the completion of this journey. Support from my family and close friends was also invaluable to reaching this goal.

More than all of that and in the midst of living through a pandemic (COVID-19) that separated me from my immediate family for almost a year, self-determination, faith in my ability, and many sleepless nights of hard work accounted for my ability to finish this thesis. I can say with confidence now, that the decision to steer the course was the best one I made in my life, and I have absolutely no regrets about journeying with the University of Sheffield in doing this doctoral degree. I never lost faith although I came close to doing so, and I am proud of myself to have reached this esteemed accomplishment.

5.12 Final Comments

This research examined the lives of three mothers parenting disabled children in Trinidad and Tobago. Specifically, it explored mothers' lived experiences and the perceptions they held around both their roles and that of government in caring for and educating disabled children in Trinidad and Tobago. Throughout this study, I felt it was important to focus on the perceptions of these mothers because their voices usually go unheard. In a nation where one percent of the population constitutes vulnerable children (CSO, 2011), there has not been any study focusing on the experiences of mothers who parent disabled children. In other words, one percent of the people has been overlooked to a large extent.

Given that disabled children and by extension their caregivers are a marginalized group and usually discriminated against, the mothers in this research became the voice and minds of their children which makes their stories worthy of exploration. Equally important was the need to capture the first-hand experiences of mothers in an attempt to expose the inefficiencies of the current system, the limited understanding, and appreciation for disability, and passive attitudes towards disabled persons.

Considering all these factors, I do hope that this research can propel policy-makers and society as a whole to take notice and employ the necessary actions to assist mothers in their caregiving journey. I felt such a great appreciation for the mothers who volunteered their time to be a part of this study and I became more inclined to make their "private troubles" a public concern through this research (Wright-Mills, 1959). Finally, I hope that mothers will stay the course in their journey and not lose hope despite being overlooked, so they can secure the possibility of a fulfilled life for their disabled children.



6 References

- Adams, D., Harris, A., & Jones, M. S. (2016). Teacher-parent collaboration for an inclusive classroom: success for every child. *Malaysian Online Journal of Educational Sciences* 4 (3), 58–71.
- Al-Kandari, H. Y., & Al-Qashan, H. (2010). Maternal self-efficacy of mothers of children with intellectual developmental disabilities, down syndrome, and autism in Kuwait. *Child and Adolescent Social Work Journal*, 27(1), 21–39. <https://doi.org/10.1007/s10560-009-0189-6>
- Alhuzail, N. A., & Levinger, M. (2018). Perpetual silence, not silence for moments: hearing loss of children as perceived by hearing Bedouin mothers. *Child and Adolescent Social Work Journal*, 35(4), 377–389. <https://doi.org/10.1007/s10560-018-0533-9>
- Alsharaydeh, E. A., Alqudah, M., Lee, R. L. T., & Chan, S. W. C. (2019). Challenges, coping, and resilience among immigrant parents caring for a child with a disability: an integrative review. *Journal of Nursing Scholarship*, 51(6), 670–679. <https://doi.org/10.1111/jnu.12522>
- Anastasiou, D., & Kauffman, J. M. (2011). A social constructionist approach to disability: Implications for special education. *Exceptional Children*, 77(3), 367–384. <https://doi.org/10.1177/001440291107700307>
- Anderson, C., & Kirkpatrick, S. (2016). Narrative interviewing. *International Journal of Clinical Pharmacy*, 38(3), 631–634. <https://doi.org/10.1007/s11096-015-0222-0>
- Angermeyer, M. C., Matschinger, H., Link, B. G., & Schomerus, G. (2014). Public attitudes regarding individual and structural discrimination: Two sides of the same coin? *Social Science and Medicine*, 103, 60–66. <https://doi.org/10.1016/j.socscimed.2013.11.014>
- Armstrong, A. C., Armstrong, D., Lynch, C., & Severin, S. (2005). Special and inclusive education in the Eastern Caribbean: Policy practice and provision. *International Journal of Inclusive Education*, 9(1), 71–87. <https://doi.org/10.1080/1360311042000302905>
- Asa, G. A., Fauk, N. K., Ward, P. R., & Mwanri, L. (2020). The psychosocial and economic impacts on female caregivers and families caring for children with a disability in Belu District, Indonesia. *PLoS ONE*, 15(11 November), 1–16. <https://doi.org/10.1371/journal.pone.0240921>
- Ault, M. J., Collins, B.C., Carter, E.W. (2013). Congregational participation and supports for children and adults with disabilities: parent perceptions. *Intellectual and Developmental Disabilities*, 51, (1) 48-61. DOI: 10.1352/1934-9556-51.01.048
- Al Sayed, B.K., AlaskarA., Alonazi. J.D. (2020). Psychosocial problems among the families of children with physical special needs: A cross-sectional survey in Saudi Arabia. *Journal of Health Informatics in Developing Countries*, 14 (2).
- Alexandra Galbin, A. (2014). An introduction to social constructionism. *Social Research Reports*, 26, p. 82-92

- Algood, C.L., Hong, J.S., M. Gourdine, R.M. & Williams, A.B. (2011). Maltreatment of children with developmental disabilities: An ecological systems analysis. *Children and Youth Services Review*, 33, p.1142–1148
- Ali, A., Hassiotis, A., Strydom, A., & Kin, M. (2012). Self-stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, 33, p. 2122–2140
- Adams, D., Harris, A., & Jones, M. S. (2016). Teacher-parent collaboration for an inclusive classroom: success for every child. *Malaysian Online Journal of Educational Sciences*, 4 (3), 58–71.
- Andrews, T. (2012). What is social constructionism? *The Grounded Theory Review*, 11, (1), p. 39
- Attia, M., Edge, J. (2017). Be(com)ing a reflexive researcher: a developmental approach to research methodology. *Open Review of Educational Research*, 4(1), p. 33-45, DOI: 10.1080/23265507.2017.1300068.
- Antwi, S.K., Hamza, K. (2015). Qualitative and quantitative research paradigms in business research: a philosophical reflection. *European Journal of Business and Management*, 7, (3).
- Baksh, I. J. (1981). Recent developments in education in Trinidad and Tobago. *International Education*, 10(2), 25. Retrieved from <https://search.proquest.com/docview/1311686895?accountid=13828>
- Baker, P. M. A., Linden, M. A., LaForce, S. S., Rutledge, J., & Goughnour, K. P. (2018). Barriers to Employment participation of individuals with disabilities: addressing the impact of employer (mis)perception and policy. *American Behavioral Scientist*, 62(5), 657–675. <https://doi.org/10.1177/0002764218768868>
- Barrett M.S., Stauffer S.L. (2009) Narrative inquiry: from story to method. In: Barrett M.S., Stauffer S.L. (Eds) Narrative inquiry in music education. *Springer, Dordrecht*. https://doi.org/10.1007/978-1-4020-9862-8_2
- Barbosa, M. A. M., Chaud, M. N., & Gomes, M. M. F. (2008). Experiences of mothers of disabled children: a phenomenological study. *Acta Paulista de Enfermagem*, 21(1), 46–52. <https://doi.org/10.1590/s0103-21002008000100007>
- Beizer, J. (2002). One's own reflections on motherhood , owning , and adoption. *Tulsa Studies in Women ' s Literature*, 21 (2), p. 237-255
- Bennett, J. M., & Volpe, M. A. (2018). Models of disability from religious tradition: introductory editorial. *Journal of Disability and Religion*, 22(2), 121–129. <https://doi.org/10.1080/23312521.2018.1482134>
- Berger, P. L. & Luckmann, T. (1966). The social construction of reality . *Penguin Books*.
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*. 15 (2), p. 219–234.

- Berghs, M., Atkin, K., Graham H., Hatton C., Thomas C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. *Public Health Research*, 4(8).
- Bergsma, S (2000). Education for all in the caribbean : Assessment 2000 Series The regular classroom as battleground for inclusive special needs education an assessment of options of special needs education in the commonwealth caribbean. in assessment. *UNESCO*.
- Beveridge, R. M., Berg, C. A., Wiebe, D. J., & Palmer, D. L. (2006). Mother and adolescent representations of illness ownership and stressful events surrounding diabetes. *Journal of Pediatric Psychology*, 31(8), 818–827. <https://doi.org/10.1093/jpepsy/jsj094>
- Blackman, S., Conrad, D. A., & Philip, L. (2017). The pre-university experiences of students with disabilities in Barbados and Trinidad. *International Journal of Special Education*, 32(2), 238–270.
- Boström, P.K., Broberg, M. Hwang.P. (2009). Parents’ descriptions and experiences of young children recently diagnosed with intellectual disability. *Child: care, health and development*. Blackwell Publishing Ltd. doi:10.1111/j.1365-2214.2009.01036.x
- Bostrom, N. (2009). Why I Want to be a Posthuman when I Grow Up. *International Library of Ethics, Law and Technology*, 2, 107–136. https://doi.org/10.1007/978-1-4020-8852-0_8
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents’ voices: ‘why and how we advocate’. A meta-synthesis of parents’ experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784–797. <https://doi.org/10.1111/cch.12383>
- Bourke-Taylor, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged child with a disability: understanding mothers’ perspectives. *Australian Occupational Therapy Journal*, 57(2), 127–136. <https://doi.org/10.1111/j.1440-1630.2009.00817.x>
- Bourke-Taylor, H. M., & Jane, F. M. (2018). Mothers’ experiences of a women’s health and empowerment program for mothers of a child with a disability. *Journal of Autism and Developmental Disorders*, 48(6), 2174–2186. <https://doi.org/10.1007/s10803-018-3486-0>
- Brannick, T., & Coghlan, D. (2007). In defense of being “native”: the case for insider academic research. *Organizational Research Methods*, 10(1), 59–74 <https://doi.org/10.1177/1094428106289253>
- Braun, V. & Clarke, V. (2012) Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds), *APA handbook of research methods in psychology, 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57-71). Washington, DC: American Psychological Association.

- Brewer, E., Brueggemann, B., Hetrick, N., & Yergeau, M. (2012). Introduction, background, and history. In B. Brueggemann (Ed.), *Arts and humanities* (pp.1–62). Sage, Thousand Oaks, CA.
- British Educational Research Association. (2011) Ethical guidelines for educational research. London. ISBN: 978-0-946671-32-8
- Brown, J. M. (2013). Recurrent grief in mothering a child with an intellectual disability to adulthood: Grieving is the healing. *Child and Family Social Work, 21*(1), 113–122. <https://doi.org/10.1111/cfs.12116>
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today, 11*(6), 461–466. [https://doi.org/10.1016/0260-6917\(91\)90009-Y](https://doi.org/10.1016/0260-6917(91)90009-Y)
- Burr, V. (2003). *Social constructionism* (2nd Ed) . Routledge.
- Carlson, J. M.& Miller, P.A. (2017). Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping. *Epilepsy & Behavior, 68* , p.168–173
- Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *Journal of Intellectual Disability Research, 59*(10), 948–957. <https://doi.org/10.1111/jir.12205>
- Carpenter, L., & Austin, H. (2007). Motherhood in the Margins. *Qualitative Inquiry, 660–674*.
- Carroll, A. (2012). World report on disability. *Irish Medical Journal, 105*(5). <https://doi.org/10.1111/j.1741-1130.2011.00320.x>
- Carroll, M. (2016). Othering and its guises. *Philosophy, Psychiatry and Psychology, 23*(3–4), 253–256. <https://doi.org/10.1353/ppp.2016.0026>
- Castillo-Montoya, M. (2016). Preparing for interview research: the interview protocol refinement framework . *The Qualitative Report, 21* (5), How to article 1, p. 811-831
- Cemalcilar, Z. (2010). Schools as socialisation contexts: Understanding the impact of school climate factors on students’ sense of school belonging. *Applied Psychology: An International Review, 59*(2), 243–272. <https://doi.org/10.1111/j.1464->
- Central Statistical Office. (2011). Trinidad and Tobago 2011 housing and population census. *Government of the Republic of Trinidad and Tobago*. Retrieved from <http://cso.gov.tt/census/2011-census-data/>
- Christensen-Strynø, M. B. (2016). Mainstreaming and misfitting Exploring disability and its intersection with gender Maria Bee Christensen-Strynø. *Journal of Media and Communication Research, 61*, 58–76.
- Choi, H., & Van Riper, M. (2016). Maternal perceptions to open-ended questions about life with down syndrome in Korea. *Qualitative Report, 21*(2), 288–298. <https://doi.org/10.46743/2160-3715/2016.2221>

- Choi, E.K. & Yoo, I.Y. (2015). Resilience in families of children with Down syndrome in Korea. *International Journal of Nursing Practice* 21, p. 532–541
- Charran, C. (2018). Special education services available in Trinidad and Tobago. *Texas Education Review*, 7(1), 116-129. <http://dx.doi.org/10.26153/tsw/18>
- Charran, C. (2018). Inclusion in Trinidad and Tobago: A dream in progress. *Texas Education Review*, 7(1), 102-106. <http://dx.doi.org/10.26153/tsw/16>
- Chenail, R.J. (2011). Interviewing the Investigator: strategies for addressing instrumentation and researcher bias concerns in qualitative research. *The Qualitative Report*, 16(1) p. 255-262.
- Christensen-Strynø, M. B. (2016). Mainstreaming and misfitting. Exploring disability and its intersection with gender. *Journal of Media and Communication Research*, 61, 58–76.
- Chowdhury, N. F. (2014). Interpretivism in aiding our understanding of the contemporary social world. *Open Journal of Philosophy*, 4, p, 432-438
- Christians, C.G. (2011). Ethics and politics in qualitative research. In Denzin & Lincoln. *The SAGE handbook of qualitative research*. Sage (4th ed.). Thousand Oaks, CA, US: *SAGE Publications, Inc.*
- Clandinin, D. J; Connelly, F. M., (2000). *Narrative Inquiry*. *John Wiley & Sons Inc, CA. Jossey-Bass.*
- Clandinin, D. J; Connelly, F. M; (1990). Stories of Experience and Narrative Inquiry. *Educational Researcher*, 19(5), 2-14.
- Clandinin, D. J., & Huber, J. (in press). Narrative inquiry. In B. McGaw, E. Baker, & P. Peterson (Eds.), *International Encyclopaedia of Education* (3rd ed.). New York, NY: Elsevier.
- Clandinin D.J., Huber,J. (2002).Narrative Inquiry: toward understanding life's artistry. *Curriculum Inquiry*, 32, (2), p. 161-169
- Clarke, V. & Braun, V. (2014) Thematic analysis. In A. C. Michalos (Ed.), *Encyclopaedia of Quality of Life and Well-Being Research* (pp. 6626-6628).
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), 297–298.
<https://doi.org/10.1080/17439760.2016.1262613>Thematic
- Cole, B. (2012). *Mothers-Teachers: Insights on Inclusion*. *Routeledge*.
- Collins, T., & Coughlan, B. (2016). Experiences of mothers in romania after hearing from medical professionals that their child has a disability. *Journal of Policy and Practice in Intellectual Disabilities*, 13(1), 4–14.
<https://doi.org/10.1111/jppi.12141>
- Cole, B. (2007). Mothers, gender and inclusion in the context of home–school relations. *Support for Learning*, 22 (4).

- Colledge, L. F.R.C.S. (1949). Annals of otology. *Rhinology & Laryngology*. 58(1), 303–303. <https://doi.org/10.1177/000348944905800131>
- Conrad, D. A., & Brown, L. I. (2011). Fostering inclusive education: principals' perspectives in Trinidad and Tobago. *International Journal of Inclusive Education*, 15(9), 1017–1029. <https://doi.org/10.1080/13603110903490721>
- Conrad, D.A., Paul, N., Bruce, M., Charles, S., Felix, K. (2010). Special schools and the search for social justice in Trinidad and Tobago: perspectives from two marginalized contexts. *Caribbean Curriculum*, 17, pp, 59–84.
- Connelly L.M. (2016). Trustworthiness in qualitative research. *Medsurg Nurs*. 25 (6), p,435-6. PMID: 30304614.
- Convention on the Rights of Persons with Disabilities and Optional Protocol. 2008. *United Nations*
- Crettenden, A., Lam, J., & Denson, L. (2018). Grandparent support of mothers caring for a child with a disability: Impacts for maternal mental health. *Research in Developmental Disabilities*, 76, 35–45. <https://doi.org/10.1016/j.ridd.2018.02.004>
- Creswell, J.W. (2009). Research Design Qualitative, Quantitative, And Mixed Methods Approaches (3rd. Ed). *Sage Publications. Inc.*
- Creswell, J. W. (2013). Qualitative inquiry and research design: Choosing among five approaches (3rd ed.). Thousand Oaks, CA: *Sage Publisher*.
- Crisp, R. (2002), A counselling framework for understanding individual experiences of socially constructed disability. *Disability Studies Quarterly*, 22, (3), p. 20-32
- CRPD. (2015). Conference of States Parties the Convention on the Rights of Persons with Disabilities Eighth session. *United Nations*.
- Currie, G., Szabo, J. (2019). 'It would be much easier if we were just quiet and disappeared': Parents silenced in the experience of caring for children with rare diseases. *Health Expectations*, 22, p.1251–1259.
- Damaskinidis, G. (2017). Qualitative research and subjective impressions in educational contexts. *American Journal of Educational Research*, 5, (12), p.1228-1233.
- Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health research*, 12 (2), p, 279-289.
- De Lisle, J., Seecharan, H., Ayodike, A.T. (2010). Is Trinidad and Tobago education system structured to facilitate optimum human capital development? New findings on the relationship between education structures and outcomes. *Conference Paper presented on March 24-26, 2010 at the 11th Annual SALISES conference, "Turbulence and Turmoil in small developing states: Going beyond survival" Hyatt Hotel, Port of Spain, Trinidad & Tobago.*
- Degener, T. (2016). A human rights model of disability. *Routledge Handbook of Disability Law and Human Rights*, November, 31–49.

<https://doi.org/10.4324/9781315612881>

- Dehghan, L., Dalvandi, A., Rassafiani, M., Hosseini, S. A., Dalvand, H., & Baptiste, S. (2015). Social participation experiences of mothers of children with cerebral palsy in an Iranian context. *Australian Occupational Therapy Journal*, 62(6), 410–419. <https://doi.org/10.1111/1440-1630.12215>
- Delaney, A. M. (2010). Perspectives of Parents of Students With Disabilities Toward Public and Homeschool Learning Environments. Thesis, i–372.
- Denzin, N.K., & Lincoln, Y. S. (2011). *The SAGE Handbook of Qualitative Research*. Sage (4th ed.). Thousand Oaks, CA, US: *SAGE Publications, Inc.*
- Denzin, N., Lincoln, Y. S. (Eds.), *Handbook of qualitative research* (pp. 105-117). *Thousand Oaks, CA: Sage*
- Denzin, N. K., & Lincoln, Y. S. Eds. (1998). The landscape of qualitative research: Theories and issues. *Thousand Oaks: Sage Publications.*
- Dillenburger, K., Mckerr, L., Jordan, J. A., Devine, P., & Keenan, M. (2015). creating an inclusive society... how close are we in relation to autism spectrum disorder? a general population survey. *Journal of Applied Research in Intellectual Disabilities*, 28(4), 330–340. <https://doi.org/10.1111/jar.12144>
- Donoghue, C. (2003). Challenging the authority of the medical definition of disability: An analysis of the resistance to the social constructionist paradigm. *Disability and Society*, 18(2), 199–208. <https://doi.org/10.1080/0968759032000052833>
- Dwyer, S. C. & Buckle, J.L. (2009). The space between: on being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8 (1)
- Economic Commission for Latin America and the Caribbean (ECLAC). (2018, July). National policy on disabled persons. *United Nations.*
- Emerson, A. (2020). ‘Room of Gloom’: Reconceptualising mothers of children with disabilities as experiencing trauma. *Journal of Loss and Trauma*, 25(2), 124–140. <https://doi.org/10.1080/15325024.2019.1658946>
- Farnsworth, C. H. (1994). Mercy killing in Canada stirs calls for changes in law. *The New York Times Archives*).<https://www.nytimes.com/1994/11/22/world/mercy-killing-in-canada-stirs-calls-for-changes-in-law.html?auth=link-dismiss-google1tap>
- Fenge, L. A., Oakley, L., Taylor, B.& Beer, S. (2019). The Impact of Sensitive Research on the Researcher: Preparedness and Positionality. *International Journal of Qualitative Research*
- Ferguson, P. M. (2002). A Place in the family: an historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education*, 36(3), 124–131. <https://doi.org/10.1177/00224669020360030201>
- Floyd, A. & Arthur, L. (2012) Researching from within: external and internal ethical engagement. *International Journal of Research & Method in Education*, 35 (2). pp. 171-180.
- Gabel, S. L. (2018). Shatter not the branches of the tree of anger: mothering, affect, and disability. *Hypatia*, 33(3), 553–568. <https://doi.org/10.1111/hypa.12410>

- Galbin, A. (2014). An introduction to social constructionism. *Social research reports*, 26, pp. 82-92
- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, 26(3), 591–609. <https://doi.org/10.1111/j.1527-2001.2011.01206.x>
- Geertz, C. (1973) Thick description: Toward an interpretive theory of culture; In Clifford Geertz, Ed., *The interpretation of cultures*. New York: Basic Books.
- George, J. & Quamina- Aiyejina, L. (2003). An analysis of primary teacher education in Trinidad and Tobago: multi-site teacher education research project (muster), country report four. *Policy Division of the Department For International Development, University Of The West Indies*
- Ghazawy, E. R., Mohammed, E. S., Mahfouz, E. M., & Abdelrehim, M. G. (2020). Determinants of caregiver burden of disabled persons in a rural district in Egypt. *BMC Public Health*, 20(1), 1–10. <https://doi.org/10.1186/s12889-020-09266-4>
- Gilson, S. F., & Depoy, E. (2000). Multiculturalism and disability: A critical perspective. *Disability and Society*, 15(2), 207–218. <https://doi.org/10.1080/09687590025630>
- Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report*, 8 (4), 597-606.
- Goodley, D., Lawthom, R., & Runswick Cole, K. (2014). Posthuman disability studies. *Subjectivity*, 7(4), 342–361. <https://doi.org/10.1057/sub.2014.15>
- Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse*, 37(1), 1–15. <https://doi.org/10.1080/01596306.2014.930021>
- Goodley, D., Tregaskis, C. (2006). Storying Disability and Impairment: Retrospective Accounts of Disabled Family Qualitative Health Research. 16, (630)
- Goodley, D., Runswick-Cole, K. (2011). Problematising policy: conceptions of ‘child’, ‘disabled’ and ‘parents’ in social policy in England. *International Journal of Inclusive Education*, 15 (1), 71-85.
- Goodley, D. (2001). “Learning difficulties”, the social model of disability and impairment: challenging epistemologies. *Disability and Society*, 16(2), 207–231. <https://doi.org/10.1080/09687590120035816>
- Goodley, D. (2012). *Disability and social theory: new developments and directions*, edited by D. Goodley, et al., Palgrave Macmillan UK. <http://ebookcentral.proquest.com/lib/york/detail.action?docID=931694>.
- Goodson, I. F., & Sikes, P. J. (2001). *Life history research in educational settings: Learning from lives*. Buckingham: Open University Press.
- Goff, S. (2016) “Child Protection and Disability Toolkit by With Scotland and the Scottish Government’s Ministerial Working Group on Child Protection and Disability, *Child abuse review*, 25. (1)74–75. Web.

- Goffman, I. (1963). Stigma, notes on the management of spoiled identity. *Simon and Shuster Inc.*
- Gona, J. K., Newton, C.R., Hartley, S.& Bunning. K. (2018). Persons with disabilities as experts-by experience: using personal narratives to affect community attitudes in Kilifi, Kenya. *BMC International Health and Human Rights* 18(18)
- Government of the Republic of Trinidad and Tobago, TT Connect. (2018). *A Person with a Disability*. Retrieved May 29, 2018 from https://www.ttconnect.gov.tt/gortt/portal/ttconnect!/ut/p/a1/jdDBCoJAEAbgp_HqjMqWdvNgpgahUeleQmNbDXNFTXv8zJtY1txm-H74GaAQAi3iNuNxxk4kizt87XZw9X0XiGBrufDRQDRzFQuJpurHsQTQCgb3ugUWUjXfUEPG_PH4Z82d-zwo4AZ1jtksmYFpzADM9XKA8F8nwk8gsEk3nQCt2ZRWr5EfVn9OmKeuVhBJ2XSdzIXjO5Ess4adEKuoGwhGE8n4In86N5O3WfAF_-E2I/dl5/d5/L2dBISvZ0FBIS9nQSEh/
- Graungaard, H., Skov. L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the new-born child is severely disabled. *Child: Care, Health and Development*, 33 (3), p. 296–307
- Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry*, 75(2), 197–215. <https://doi.org/10.1111/j.1475-682X.2005.00119.x>
- Green, S. E. (2003). “What do you mean ‘what’s wrong with her?’”: Stigma and the lives of families of children with disabilities. *Social Science and Medicine*, 57(8), 1361–1374. [https://doi.org/10.1016/S0277-9536\(02\)00511-7](https://doi.org/10.1016/S0277-9536(02)00511-7)
- Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64(1), 150–163. <https://doi.org/10.1016/j.socscimed.2006.08.025>
- Greene, M.J. (2014). On the inside looking in: methodological insights and challenges in conducting qualitative insider. *The Qualitative Report* , 19, (15), p. 1-13 .
- Grinker, R. R. (2020). Autism, “stigma,” disability a shifting historical terrain. *Current Anthropology*, 61(S21), S55–S67. <https://doi.org/10.1086/705748>
- Groce, N., Kett, M., Lang, R., Trani, J. F. (2011). Disability and poverty: the need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*, 32, (8), pp 1493–1513
- Guba, E. G., & Lincoln, Y. S. (1986). But is it rigorous? trustworthiness and authenticity in naturalistic evaluation. D. D. Williams (Ed). *Naturalistic Evaluation, New Directions for Program Evaluation*, (30). *San Francisco. Jossey-Bass.*
- Guba, E. G. (1981). Criteria for assessing naturalistic inquiries. *Education Communication and Technology*, 29(2), 75–91. <http://eric.ed.gov/?id=ED297007>
- Guba, E. G., & Lincoln, Y. S. (2001). Guidelines and checklist for constructivist (a . K . A . Fourth

generation) evaluation. *Evaluation*, November, 1–15.
http://www.wmich.edu/evalctr/archive_checklists/constructivisteval.pdf

- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. in n. k. denzin & y. s. lincoln (eds.), *Handbook of qualitative research* (pp. 105–117). *Thousand Oaks, CA, US: Sage*.
<https://doi.org/http://www.uncg.edu/hdf/facultystaff/Tudge/Guba%20&%20Lincoln%201994.pdf>
- Guetterman, T., (2015). Descriptions of sampling practices within five approaches to qualitative research in education and the health sciences. *Educational Psychology Papers and Publications*. 263.
<https://digitalcommons.unl.edu/edpsychpapers/263>
- Gupta, V. B. (2011). How Hindus cope with disability. *Journal of Religion, Disability and Health*, 15(1), 72–78. <https://doi.org/10.1080/15228967.2011.540897>
- Guyotte, K. W. (2015). Becoming ... in the midst/wide-awake/in-between: an in-process narrative inquiry. *Narrative Works: Issues, Investigations, & Interventions* 5(2), 71–85,
- Halstead, E. J., Griffith, G. M., & Hastings, R. P. (2018). Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, 64(4–5), 297–305.
<https://doi.org/10.1080/20473869.2017.1329192>
- Hatun, O., Yavuz Birben, F., İnce, Z., & Kalkan Yeni, G. (2016). The Ticket to Heaven: A Spiritual Resource for Coping with Disability. *Spiritual Psychology and Counseling*, 1(2), 209–236. <https://doi.org/10.12738/spc.2016.2.0013>
- Hellawell, D. (2006). Inside–out: analysis of the insider–outsider concept as a heuristic device to develop reflexivity in students doing qualitative research, *Teaching in Higher Education*, 11(4), p, 483-494, DOI: 10.1080/13562510600874292
- Heiman, T. (2002). Parents of children with disabilities: resilience, coping, and future expectations . *Journal of Developmental and Physical Disabilities* 14(2):159-171
- Harvey, C. (2015). Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective. *Agenda*, 29(2), 89–100.
<https://doi.org/10.1080/10130950.2015.1039871>
- Harvey, C. (2020). The uncanny effect of disability: uncomfortable maternal love for a disabled child. *Contemporary Psychoanalysis*, 56(1), 1–28.
<https://doi.org/10.1080/00107530.2020.1717218>
- Harvey, C., & Long, C. (2020). “Sharing the unsharable”: Subjectivity and the return of the abject in mothers of physically disabled children. *Psychoanalysis, Culture and Society*, 25(3), 460–479. <https://doi.org/10.1057/s41282-020-00180-7>
- Hengst, J. A., Devanga, S., & Mosier, H. (2015). Thin versus thick description: analyzing representations of people and their life worlds in the literature of communication sciences and disorders. *American Journal of Speech-Language Pathology*, 24(4), S838.
- Harvey, C. (2015). Maternal subjectivity in mothering a child with a disability: A

- psychoanalytical perspective. *Agenda*, 29(2), 89–100.
<https://doi.org/10.1080/10130950.2015.1039871>
- Harvey, C. (2020). The uncanny effect of disability: uncomfortable maternal love for a disabled child. *Contemporary Psychoanalysis*, 56(1), 1–28.
<https://doi.org/10.1080/00107530.2020.1717218>
- Harvey, C., & Long, C. (2020). “Sharing the unsharable”: Subjectivity and the return of the abject in mothers of physically disabled children. *Psychoanalysis, Culture and Society*, 25(3), 460–479. <https://doi.org/10.1057/s41282-020-00180-7>
- Hassan, A. A., Hamid, A. M., & Eltayeb, N. H. (2021). Burden on parenting of children with special needs : *EAS Journal of Nursing and Midwifery*, 3 (2)
- Hockey, J. (1993) Research methods -- researching peers and familiar settings, *Research Papers in Education*, 8 (2), p. 199-225, DOI: 10.1080/0267152930080205
- Humphrey, C. (2007). Insider-outsider. *Action Research*, 5(1), 11–26.
<https://doi.org/10.1177/1476750307072873>
- Hunt, X. & Watermeyer, B. (2017) A web of gaps: a discussion of research strands concerning Global South families with a disabled child, *Global Health Action*, 10(1), 1337355, DOI: 10.1080/16549716.2017.1337355
- Isgro, K. (2015). From a caretaker’s perspective: Mothers of children with down syndrome as advocates. *Women & Language*, 38(1), 63–83.
- Jackson, M. (2018). Models of disability and human rights: informing the improvement of built environment accessibility for people with disability at neighborhood scale? *Laws*, 7(1), 10. <https://doi.org/10.3390/laws7010010>
- Jahng, K. E. (2020). South Korean mothers’ childhood abuse experience and their abuse of their children with intellectual and developmental disabilities: Moderating effect of parenting self-efficacy. *Child Abuse and Neglect*, 101
- James, F.. (2010). Leading educational improvement in Trinidad and Tobago. *School Leadership & Management*, 30(4), 387–398.
<https://doi.org/10.1080/13632434.2010.497481>
- Janesick, V.J. (2011). “Stretching’ exercises for qualitative researchers (3rd ed). *SAGE Publications Inc.*
- Jensen, M. P., Brunklaus, A., Dorris, L., Zuberi, S. M., Knupp, K. G., Galer, B. S., & Gammaitoni, A. R. (2017). The humanistic and economic burden of Dravet syndrome on caregivers and families: Implications for future research. *Epilepsy and Behavior*, 70, p. 104–109. <https://doi.org/10.1016/j.yebeh.2017.02.003>
- Jeong, K.L (2016). Understanding narrative inquiry: the crafting and analysis of stories as research. *Sage Publications, Inc.*
- Jeske, D. (1996). Libertarianism, self-ownership, and motherhood. *Social Theory and Practice* , 22 (2)
- Johnstone, C. J. (2010). Inclusive education policy implementation: Implications for teacher workforce development in Trinidad and Tobago. *International Journal of Special Education*, 25(3), 33-42.

- Junaidi, A. R., & Dewantoro, D. A. (2020). Parents' perceptions of children with disabilities. *Advances in Social Science, Education and Humanities Research*, 508
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45, (3)
- Kamenopoulou, L., & Dukpa, D. (2018). Karma and human rights: Bhutanese teachers' perspectives on inclusion and disability. *International Journal of Inclusive Education*, 22 (3), 323–338. <https://doi.org/10.1080/13603116.2017.1365274>
- Khan, G., Isaacs, D., Makoae, M. G., Fluks, L. L., Mokhele, T., & Mokomane, Z. (2020). Service providers' perceptions of families caring for children with disabilities in resource-poor settings in South Africa. *Child and Family Social Work*, 25(4), 823–831. <https://doi.org/10.1111/cfs.12761>
- Khan, G., Isaacs, D., Makoae, M. G., Fluks, L. L., Mokhele, T., & Mokomane, Z. (2020). Service providers' perceptions of families caring for children with disabilities in resource-poor settings in South Africa. *Child and Family Social Work*, 25(4), 823–831. <https://doi.org/10.1111/cfs.12761>
- Khubulava, G. G. (2017). Disabled child and the society: Relationships and socialization. *Pediatric Traumatology, Orthopaedics and Reconstructive Surgery*, 5(3), 66–73. <https://doi.org/10.17816/PTORS5366-73>
- Kikuchi, Y., & Noriuchi, M. (2016). The neuroscience of maternal love. *Neuroscience Communications*, 1: e991
- Kim, K. M., & Hwang, S. K. (2019). Being a 'good' mother: Immigrant mothers of disabled children. *International Social Work*, 62(4), 1198–1212. <https://doi.org/10.1177/0020872818769707>
- Kim, J.H. (2016). Understanding narrative inquiry. *SAGE Publications Ltd.*
- Koch, K. A. (2020). "The voice of the parent cannot be undervalued": pre-service teachers' observations after listening to the experiences of parents of students with disabilities. *Societies*, 10(3), 50. <https://doi.org/10.3390/soc10030050>
- Kristeva, J. (2013). A tragedy and a dream: Disability revisited. *Irish Theological Quarterly*, 78(3), 219–230. <https://doi.org/10.1177/0021140013484427>
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76(4), 564–575. <https://doi.org/10.1037/0002-9432.76.4.564>
- Lad, P. M., & Dahl, R. (2014). Overcoming language barriers in the informed consent process: regulatory and compliance issues with the use of the "short form." *Accountability in Research*, 21(5), 315–320. <https://doi.org/10.1080/08989621.2013.848801>
- Lapadat, J. C., & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positionings. *Qualitative Inquiry*, 5(1), 64–86. <https://doi.org/10.1177/107780049900500104>
- Lalvani, P. (2011). Constructing the (m)other. *Narrative Inquiry*, 21(2), 276–293. <https://doi.org/10.1075/ni.21.2.06lal>

- Landsman .G.H. (2009). *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. Taylor & Francis, Routledge
- Landsman,G.(1998).Reconstructing motherhood in the age of 'perfect' babies: mothers of infants and toddlers with disabilities. *Journal of women in culture and society*, 24(1)
- Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities*, 26(2–3), 121–139. <https://doi.org/10.1007/s10912-005-2914-2>
- Lapadat, J. C. , & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positioning. *Qualitative Inquiry*,5,64–86.
- Lavia, J. (2007). Inclusive Education in Trinidad and Tobago (Chp.7). In . L. Barton and F. Armstrong (Eds.), *Policy, Experience and Change*, p.107–122.
- Leonardi, M., Bickenbach, J., Ustun, T. B., Kostanjsek, N., & Chatterji, S. (2006). The definition of disability: what is in a name? *Lancet*, 368 (9543), 1219–1221. [https://doi.org/10.1016/S0140-6736\(06\)69498-1](https://doi.org/10.1016/S0140-6736(06)69498-1)
- Levitt, J. M. (2017). Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver. *Disability and Society*, 32(4), 589–594. <https://doi.org/10.1080/09687599.2017.1300390>
- Libert, R. A. (2007). Practice of education in Trinidad and Tobago: Does it infringe on the human rights of disabled students? *Libert Education*
- Lincoln, Y. S., & Guba, E. G. (1986). Trustworthiness and Naturalistic Evaluation. *Program*, 30. <https://doi.org/10.1002/ev.1427>
- Lindsay, G. M., & Schwind, J. K. (2016). Narrative Inquiry: Experience matters. *The Canadian Journal of Nursing Research = Revue Canadienne de Recherche En Sciences Infirmieres*, 48(1), 14–20. <https://doi.org/10.1177/0844562116652230>
- Lee, J. (2013). Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. *Research in Developmental Disabilities*, 34(11), 4255–4273. <https://doi.org/10.1016/j.ridd.2013.09.008>
- Li, X., Lam, C. B., Kien, K., Chung, H., & Leung, C. (2019). Linking parents' self-stigma to the adjustment of children with disabilities. *American Journal of Orthopsychiatry*, 89(2), 212–221. <https://doi.org/10.1037/ort0000386>
- Lee, H. (2006). *To kill a mockingbird*. New York: Harper Perennial Modern Classics,
- Lincoln, Y.S.& Guba, E.G. (1986.) But is it rigorous? trustworthiness and authenticity in naturalistic evaluation in Williams D. D. (Ed). *Naturalistic evaluation, new directions for program evaluation*, No. 30. San Francisco: Jossey-Bass.
- Lincoln, Y. S.& Guba, E.G. (1988). Criteria for assessing naturalistic inquiries as reports. *Paper presented at the Annual Meeting of the American Educational Research Association*. New Orleans, LA, 5-9.
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: SAGE.

- Lyll, K., Schmidt, R.J., Hertz-Picciotto, I. (2014). Maternal lifestyle and environmental risk factors for autism spectrum disorders. *International Journal of Epidemiology*, 443–464
- Lyle Duque, R. (2009). Catherine Kohler Riessman (2008). Narrative methods for the human sciences. *Forum Qualitative Sozialforschung*, 11(1).
<https://doi.org/10.17169/fqs-11.1.1418>
- Mack, N., Woodson, C., MacQueen, K.M., Guest, G. & Namey, E. (2005), Qualitative research methods: a data collector’s field guide, *Family Health International*.
- McCullagh, C.B.(2000), Bias in historical description, interpretation, and explanation *History and Theory*, 39, (1), pp. 39-66
- Mishler, E.G. (1990). Validation in inquiry-guided research: the role of exemplars in narrative studies. *Harvard Educational Review*, 60, (4)
- Merton, R. (1972). Insiders and outsiders: a chapter in the sociology of knowledge. *American Journal of Sociology*, 78 (1), p 9-47
- Milligan, L. (2016) Insider-outsider-inbetweener? Researcher positioning, participative methods and cross-cultural educational research, *Compare: A Journal of Comparative and International Education*, 46 (2), 235-250, DOI: 10.1080/03057925.2014.928510
- Moen , T. (2006). Reflections on the narrative research approach. *International Journal of Qualitative Methods*, 5 (4)
- Mishler, E.G. (1990). Validation in inquiry-guided research: the role of exemplars in narrative studies. *Educational Review* , 60 (4)
- McCusker, K., & Gunaydin, S. (2015). Research using qualitative, quantitative or mixed methods and choice based on the research. *Perfusion*, 30 (7), 537 - 542. <https://doi.org/10.1177/0267659114559116>
- McDougall, D. H.(2017). Conceptualisations of ‘normal’ for disabled persons in the context of special education. *International Journal of Social Science and Humanity*, 7,(6).
- Munyi, C.W. (2012). Past and Present perceptions towards disability: a historical perspective. *Disability Studies Quarterly*, 32 (2)
- Madi, S., M Mandy, A., & Aranda, K. (2019). The perception of disability among mothers living with a child with cerebral palsy in Saudi Arabia. *Global Qualitative Nursing Research*, 6. <https://doi.org/10.1177/2333393619844096>
- Mack, K. J.. (2014). Programs and social supports for adults with a learning disability in Trinidad: policy review and analysis. *Canadian Journal of Disability Studies*, 3(2), 62. <https://doi.org/10.15353/cjds.v3i2.157>
- Mokhtari,M., &Fatemeh Abootorabi,F. (2019). Lived experiences of mothers of children with cerebral palsy in iran: a phenomenological study. *Child & Youth Services*, 40, (3),p. 224–244

- MSDFS-Ministry of Social Development and Family Services. (2017). A guide to social programmes and services of the ministry of social development and family services. Port of Spain: *Ministry of Social Development and Family Services, The Government of Trinidad and Tobago*
- MSDFS (2018.) National policy on disabled persons. Trinidad and Tobago.
- Nazzal, M. S., & AL-Rawajfah, O. M. (2018). Lived experiences of Jordanian mothers caring for a child with disability. *Disability and Rehabilitation*, 40(23), 2723–2733. <https://doi.org/10.1080/09638288.2017.1354233>
- Neile, C. S., & Novak, D. (2013). Toward a methodology of storytelling performance criticism. *Storytelling, Self, Society*, 9(1), 129-134. Retrieved from <https://search-proquest-com.sheffield.idm.oclc.org/docview/1563701403?accountid=13828>
- Nowell, L., Norris, J., White, D., & Moules, N. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, 16(1), 160940691773384–. <https://doi.org/10.1177/1609406917733847>
- Njelesani, J., Leckie, K., Drummond, J., & Cameron, D. (2015). Parental perceptions of barriers to physical activity in children with developmental disabilities living in Trinidad and Tobago. *Disability and Rehabilitation*, 37(4), 290–295. <https://doi.org/10.3109/09638288.2014.918186>
- Oliver, M. (1990). The Individual and Social Models of Disability. *Paper Presented At Joint Workshop of the Living Options Group and The Research Unit of The Royal College of Physicians on People With Established Locomotor Disabilities in hospitals.*
- Oliver, M. (2012). Creating a society for all: disability and economy. *In Disability & Society*, 27, (6). <https://doi.org/10.1080/09687599.2012.714254>
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28
- Oliver, M., & Barnes, C. (2010). Disability studies, disabled people and the struggle for inclusion. *British Journal of Sociology of Education*, 31(5), 547–560. <https://doi.org/10.1080/01425692.2010.500088>
- Orb, A; Eisenhauer, L.& Wynaden, D. (2000). Ethics in Qualitative Research. *Journal of Nursing Scholarship*, 33 (1), p. 93-96.
- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health and Illness*, 37(3), p. 385–403. <https://doi.org/10.1111/1467-9566.12199>
- Owusu, I., Enoch, A., Mprah, W. K., & Vampere, H. (2018). Factors influencing parents' perceptions on the education of children with disability in the Wa West District of Ghana. *International Journal of Special Education*, 33(3), p. 675–686.
- Packwood, A., Sikes, P. (1996) Adopting a postmodern approach to research. *International Journal of Qualitative Studies in Education*, 9 (3), p, 335-345, DOI: 10.1080/0951839960090308

- Patton, M.Q. (2002). *Qualitative research and evaluation methods*, Ed 3. *SAGE Publications INC*
- Patton, M.Q. (1999) Enhancing the quality and credibility of qualitative analysis. *HSR: Health Services Research* 34 (5) p. 1189-1208
- Parey, B. (2021). Parents' perspectives on wellbeing among children with disabilities in trinidad : using sen's capability approach and mixed methods. *Child Indicators Research*, 0123456789. <https://doi.org/10.1007/s12187-020-09801-0>
- Parey, B. (2020). Using sen's capability approach to assess wellbeing among working-age disabled persons in Trinidad. *Social Indicators Research*, 151(3), 1129–1148. <https://doi.org/10.1007/s11205-020-02418-4>
- Parish, S. L., Andrews, M. E., & Rose, R. A. (2010). TANF's impact on low-income mothers raising children with disabilities. *Exceptional Children*, 76(2), 234+. https://link.gale.com/apps/doc/A216410967/EAIM?u=yorku_main&sid=EAIM&xid=7be6d5d7
- Pedro, J. & Conrad, D. (2006). Special education in Trinidad and Tobago. Educational vision and change. *Childhood Education* 82 (6)
- Perlman, M., Fletcher, B., Falenchuk, O., Brunsek, A., McMullen, E., & Shah, P. S. (2017). Child-staff ratios in early childhood education and care settings and child outcomes: A systematic review and meta-analysis. *PLoS ONE*, 12(1), 1–24. <https://doi.org/10.1371/journal.pone.0170256>
- Persons, H. (2018). Persons with Disabilities in Trinidad & Tobago: A Situational Analysis. . *Commonwealth of Learning*.
- Pierce, J.L., Kostova T.& Dirks, K.T. (2003). The state of psychological ownership: integrating and extending a century of research. *Review of General Psychology*, 7(1),p. 84-107. doi:10.1037/1089-2680.7.1.84
- Pillay,D., Girdler,,S., Collins ,M.& Leonard, H. (2012). “It’s not what you were expecting, but it’s still a beautiful journey”: the experience of mothers of children with Down syndrome. *Disability & Rehabilitation*, 34(18): 1501–1510
- Priestly, M. (2001). *Disability and the life course global perspectives*. *Cambridge University Press*
- Poland, B. D. (1995). Transcription quality as an aspect of rigor in qualitative research. *Qualitative Inquiry*, 1, p. 290–310.
- Pope, C., Ziebland, S., Mays, N. (2000). Qualitative research in health care Analyzing qualitative data. From *Qualitative Research in Health Care* (2ND ED). *BMJ*, 320
- Punch, M. (1994). Politics and ethics in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research*. Newbery Park, CA: *SAGE*.
- Qiong, O. (2017). A Brief Introduction to Perception. *Studies in Literature and Language*, 15(4), 18–28. <https://doi.org/10.3968/10055>
- Quaina-Aiyejina, L. (2000). *Education for All in The Caribbean: Assessment 2000 Monograph Series*. *UNESCO*

- Raff, N.S., Mire, S.S., Frankel, L., McQuillin S.D, Loveland, K., Daire, A., Grebe, S. & Rosenbrock, G. (2021). Understanding perceptions underlying the self-reported stress among parents of adolescents with autism spectrum disorder: Considerations for supporting families. *Research in Autism Spectrum Disorders*, 84, 101770
- Retief, M., & Letšosa, R. (2018). Models of disability: A brief overview. *HTS Teologiese Studies / Theological Studies*, 74(1), 1–8. <https://doi.org/10.4102/hts.v74i1.4738>
- Richards, J. C. (2011). "Every word is true": stories of our experiences in a qualitative research course. *The Qualitative Report*, 16 (3), 782-819. Retrieved from <https://nsuworks.nova.edu/tqr/vol16/iss3/9>
- Riddle, C. A. (2020). Why we do not need a ‘stronger’ social model of disability. *Disability and Society*, 35(9), 1509–1513. <https://doi.org/10.1080/09687599.2020.1809349>
- Roopnarine, J. L., Logie, C., Davidson, K. L., Krishnakumar, A., & Narine, L. (2015). Caregivers’ Knowledge about children’s development in three ethnic groups in Trinidad and Tobago. *Parenting*, 15(4), 229–246. <https://doi.org/10.1080/15295192.2015.1053331>
- Rubin, H.J. and Rubin, I.S. (2012) Qualitative interviewing: The art of hearing data. 3rd Edition. *Sage Publications, Thousand Oaks*.
- Runswick-Cole, K., & Ryan, S. (2019). Liminal still? Unmothering disabled children. *Disability and Society*, 34(7–8), 1125–1139. <https://doi.org/10.1080/09687599.2019.1602509>
- Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education*, 30, (3)
- Ryan, S. (2005). “People don’t do odd, do they?” mothers making sense of the reactions of others towards their learning disabled children in public places. *Children’s Geographies*, 3(3), 291–305. <https://doi.org/10.1080/14733280500352920>
- Ryan, S., & Cole, K. R. (2009). From advocate to activist? mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43–53. <https://doi.org/10.1111/j.1468-3148.2008.00438.x>
- Saldana, J. (2016). The coding manual for qualitative researchers. 3rd ed. *London, U.K. SAGE*
- Saleh, M. C., & Bruyère, S. M. (2018). Leveraging employer practices in global regulatory frameworks to improve employment outcomes for people with disabilities. *Social Inclusion*, 6(1), 18–28. <https://doi.org/10.17645/si.v6i1.1201>
- Savari, K., Naseri, M., & Savari, Y. (2021). Evaluating the role of perceived stress, social support, and resilience in predicting the quality of life among the parents of disabled children. *International Journal of Disability, Development and Education*, 00(00), 1–15. <https://doi.org/10.1080/1034912X.2021.1901862>

- Scotch, R. K. (2000). Models of disability and the Americans with disabilities Act. *Berkeley Journal of Employment & Labor Law*, 21(1), 213–222.
<https://doi.org/10.15779/Z38V91G>
- Seepersad, R. (2016). Crime and violence in Trinidad and Tobago. *IDB Series on Crime and Violence in the Caribbean*. <https://publications.iadb.org/handle/11319/7772>
- Seetahal, K., & Charran, C. (2018). The unknown and unemployed masses with disabilities in Trinidad and Tobago. *Texas Education Review*, 7(1), 130-139.
- Sikes, P. (2010) ‘The ethics of writing life histories and narratives in educational research’ in Bathmaker, A. & Harnett, P. (Eds) Exploring learning, identity and power through life history and narrative research. *London, Routledge/Falmer*
- Sikes, P. (2004). Methodology, procedures and ethical concerns, from Opie, Clive (Ed.), *Doing education research: a guide for first time researchers*, p. 15-33. *London; SAGE Publication Ltd.*
- Sikes, P. & K Gale, (2006). Narrative Approaches to Education Research. *Faculty of Education, University of Plymouth*
- Singal, N. (2009). Education of Children with disabilities in India . *UNESCO*
- Shah, S., Tsitsou, L., & Woodin, S. (2016). ‘I can’t forget’: Experiences of violence and disclosure in the childhoods of disabled women. *Childhood*, 23(4), 521–536.
<https://doi.org/10.1177/0907568215626781>
- Shakespeare, T. (1994). Cultural representation of disabled people: Dustbins for disavowal? *Disability & Society*, 9(3), 283–299.
<https://doi.org/10.1080/09687599466780341>
- Shakespeare, T. (2002). The social model of disability: an outdated ideology? *Research in Social Science and Disability*, (2), pp. 9-28
- Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2, 9–28.
- Shakespeare, T. (1994). Cultural representation of disabled people: dustbins for disavowal? *Disability & Society*, 9(3), 283–299.
<https://doi.org/10.1080/09687599466780341>
- Shannon, P., Hambacher, E. (2014). Authenticity in constructivist inquiry: assessing an elusive construct. *The Qualitative Report*, 19, (26), p. 1-13.
<http://www.nova.edu/ssss/QR/QR19/shannon26.pdf>
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* 22, p. 63–75
- Sinason, V. (2002) Some reflections from twenty years of psychoanalytic work with children and adults with a learning disability. *Disability Studies Quarterly*, 22,(3), p. 38-45
- Singh, R., Chopra, G. (2020). Living the exclusion while growing up with physical disability: a case study using life story approach. *The National Life Skills, Value Education & School Wellness Program*, 6, (1)

- Sigurjónsdóttir, H. B., & Rice, J. G. (2018). Evidence of neglect as a form of structural violence: parents with intellectual disabilities and custody deprivation. *Social Inclusion*, 6(2), 66–73. <https://doi.org/10.17645/si.v6i2.1344>
- Sipal, R. F., & Sayin, U.. (2013). Impact of perceived social support and depression on the parental attitudes of mothers of children who are deaf. *Journal of Child and Family Studies*, 22(8), 1103–1111. <https://doi.org/10.1007/s10826-012-9672-3>
- Smart, J. F. (2009). The Power of Models of Disability. *Journal of Rehabilitation* ,75, (2) p. 3-11.
- Smith, B & Bundon, A 2017, Disability models: Explaining and understanding disability sport in different ways. in Brittain & A Beacom (eds), *Palgrave Handbook of Paralympic Studies*. PalgraveStacey Blackman, S., Dennis A Conrad,. D.A.& Lisa Philip, L. (2017). The pre-university experiences of students with disabilities in Barbados and Trinidad. *International Journal of Special Education*, 32, (2),
- Stake, R. (1978) The case study method in social inquiry. *Educational Researcher*, 7.
- Staniland, L. (2009). Public Perceptions of Disabled People: Evidence from the British Social Attitudes Survey 2009. *Office for Disability Issues HM Government*, 1–104. <http://odi.dwp.gov.uk/docs/res/ppdp/ppdp.pdf>
- Steinbach, M. (2012) Obstacles to change in teacher education in Trinidad and Tobago. *The International Education Journal: Comparative Perspectives*, 11(1), 69–81. ISSN 1443-1475 © 2012 www.iejcomparative.org
- Stuckey, H.L. (2013). Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes*, 1, p. 56 - 59
- Stutchbury, K., Fox, A. (2009): Ethics in educational research: introducing a methodological tool for effective ethical analysis. *Cambridge Journal of Education*, 39 (4), 489-504
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect*, 24(10), 1257–1273. [https://doi.org/10.1016/S0145-2134\(00\)00190-3](https://doi.org/10.1016/S0145-2134(00)00190-3).
- Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science and Medicine*, 256(May), 113034. <https://doi.org/10.1016/j.socscimed.2020.113034>
- Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling*, 87(2), 233–238. <https://doi.org/10.1016/j.pec.2011.08.015>
- Trémolière, B., Neys, W. De, & Bonnefon, J. F. (2012). Mortality salience and morality: Thinking about death makes people less utilitarian. *Cognition*, 124(3), 379–384. <https://doi.org/10.1016/j.cognition.2012.05.011>
- Tsai, W. C., Tsai, J. L., & Lotus Shyu, Y. I. (2008). Integrating the nurturer-trainer

- roles: Parental and behavior/symptom management processes for mothers of children with autism. *Social Science and Medicine*, 67(11), 1798–1806.
<https://doi.org/10.1016/j.socscimed.2008.07.015>
- Tuhiwai-Smith, L. (2012). *Decolonizing Methodologies: Research and Indigenous Peoples*. 2nd ed. London: Zed Books
- United Nation (1994). The Salamanca statement and framework for action on special needs education. Adopted by the world conference on special needs education: access and quality. *United Nations Educational, Scientific and Cultural Organization (UNESCO) Salamanca, Spain*.
- United Nations (2008). Convention on the rights of disabled persons and optional protocol. *United Nations*
- UNESCO. (2000). The Dakar Framework for Action. *UNESCO*.
<http://unesdoc.unesco.org/images/0012/001211/121147e.pdf>
- UNESCO-Economic Commission for Latin America and The Caribbean (ECLAC). (2009). A further study on disability in the Caribbean: rights, commitment, statistical analysis, and monitoring. *UNESCO*
- UNICEF (2007). Promoting the Rights of Children with Disabilities. *UNICEF*
- UNICEF (2017) Situation analysis of children in Trinidad and Tobago. *UNICEF*.
- Unluer, S. (2012). Being an insider researcher while conducting case study research. *The Qualitative Report*, 17(29), p. 1-14. Retrieved from
<https://nsuworks.nova.edu/tqr/vol17/iss29/2>
- Van Trigt, P., Kool, J., & Schippers, A. (2016). Humanity as a contested concept: Relations between disability and 'being human.' *Social Inclusion*, 4(4)
- Webster, L.M., Mertova, P. (2007). Using narrative inquiry as a research method: An introduction to using critical event narrative analysis in research on learning and teaching. *Routledge*, p. 1-11
- Williams, S. (2007). Trinidad and Tobago Caribbean symposium on inclusive education. *UNESCO International*.
- Woodgate, R.L., Edwards, M., Ripat, J.D., Borton, B., Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15(197). DOI 10.1186/s12887-015-0514-
- World Health Organization. (2001). World Report on Child Injury Prevention. *World Health Organization, Geneva*
<https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf>
- World Health Organization. (2011). World report on disability. *The World Bank*, WHO (2002). Towards a common language for functioning, disability and health: *ICF. International Classification, World Health Organization*
<http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>
- Wright Mills, C. (1959). *The sociological imagination*. Oxford University Press.

- Yoosefi lebni, J., Ziapour, A., Khosravi, B., & Rahimi khalifeh kandi, Z. (2020). Lived experience of mothers of children with disabilities: a qualitative study of Iran. *Journal of Public Health (Germany)*. <https://doi.org/10.1007/s10389-020-01215-0>
- Yousafzai, A., Farrukh, Z., & Khan, K. (2011). A Source of strength and empowerment? An exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. *Disability & Rehabilitation*, 33(12), 989-998.
- Zulfia, R. (2020). Mother's experience in caring for children with special needs: a literature review. *IJDS Indonesian Journal of Disability Studies*, 7(1), 8–18. <https://doi.org/10.21776/ub.ijds.2019.007.01.2>
- Zvoleyko, E. V., Kalashnikova, S. A., & Klimenko, T. K. (2016). Socialization of students with disabilities in an inclusive educational environment. *International Journal of Environmental and Science Education*, 11(14), 6469–6481.

7 Appendices

7.1 Appendix I – Participant's Information Sheet



Western Bank Sheffield S10 2TN UK

Department: Educational Studies

Email: themesa.neckles@sheffield.ac.uk

Judy D. Taklalsingh

Research Project

Participant Information Sheet

Research Project Title

*Exploring Three Mothers' Perceptions and Lived Experiences of
Caring for and Educating their Disabled Child in
Trinidad and Tobago*

Invitation paragraph

You are being invited to take part in a research project on disability. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

The aim of the project is to gain insight into the experiences and perceptions of mothers who parent a child with a disability (disabled children) by understanding how mothers care for and educate their children. It also seeks to get a deeper understanding of disability itself in Trinidad and Tobago. There is also a lack of comprehensive data and research on disability in Trinidad and Tobago and specifically on mothers of disabled children. It is probably one reason why disability is so misunderstood by many people in Trinidad and Tobago. By agreeing to tell your story and share your experiences, I do hope that the findings from the research can bring greater understanding of disability and how it impacts on the way mothers educate and care for their children.

The interviews for this project may be for a duration of 1-2 months, and will be limited to one or two sessions depending on your availability and time. The final results may take about 1-3 years to complete after which the result will be shared with you.

Why have I been chosen?

You were chosen based on your observable involvement with disability networks. It was felt that your contribution and your story will be valuable for this research project on disability. There are two other participants who are similarly chosen for this project.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form as well. You can still withdraw at any time if you feel you cannot continue and you do not have to give a reason unless you wish to. You can quit without having to pay for anything and you will not be held liable for anything. Your participation is entirely voluntary.

What will happen to me if I take part?

I will conduct interview/s with you at a convenient time to you. I plan to do a maximum of two interviews that may last up to one hour each and over a two-month period. If this can be shortened, then we can work out a schedule. However, most of the time, one interview is sufficient. As a participant you will be asked to tell me your story about your experiences in raising your child and your views about disability and the government. However, I will have a few guiding questions that I will direct to you to get the answers that I will be seeking for the research. This is just to maintain focus in the event we are drifting too far.

If you have to meet me at a place to be interviewed, I will cover your travel expenses. I will expect you to tell me about your experiences as it happened and not say what you think I want to hear. I can assure you that everything will be treated as confidential and secret. The interviews will also be recorded. The recorded interview will then be transcribed by me, that is I will write down all we (both you and I) talk about. Following this I will then proceed to analyse the data (that is critically look at what you tell me) and then write what I find from the interviews conducted with you and the other participants.

What do I have to do?

You will have to put aside time for being interviewed, maybe about an hour or two at maximum. I plan to conduct just none or two sessions. If more time is needed this will be discussed with you. However, the time can be flexible where we can do one-hour or two-hours sessions if that is more suitable. You may have to agree to arrange a suitable venue for the interview/s to be conducted, possibly somewhere quiet and private where there is little distraction.

What are the possible disadvantages and risks of taking part?

Some of the discomfort you may experience in the interview/s may include:
emotional stress (maybe anger) in recounting your experiences
time management
unreal or high expectations that something can or will be done to immediately help you
Issues of trust (with the researcher or the process)
Feelings to maybe discontinue with the interview and withdraw from the research

What are the possible benefits of taking part?

Whilst there are no immediate benefits for you or others participating in the project, it is hoped that this work will:

- Bring a sense of satisfaction of having contributed to research on disability in Trinidad and Tobago
- Sharing your story may encourage others to do the same and talk about disability as a natural part of life
- Possibly think of ways to promote the rights of children and adults with disabilities in Trinidad and Tobago

What happens if the research study stops earlier than expected?

If for some unforeseen reason I have to stop the research suddenly, I will inform and explain to you the reason/s for its cessation.

What if something goes wrong?

If you should have any complaint or questions about the process, please feel comfortable to contact me at 868-685-3947. You can also contact my supervisor, Dr. Themesa Neckles, Email: themesa.neckles@sheffield.ac.uk, at the University of Sheffield

Will my taking part in this project be kept confidential?

All the information that I collect about you during the course of the research will be kept strictly confidential up to a certain point. That means that you will never be identified in the research but the information you give me can be used in reports or publications. However, no one will have access to your personal information without your consent. Even if the entire report or parts of it are used in publication, your identity will be protected and you will have to give your permission before it is used. Confidentiality will be maintained by anonymity, that is, I will use pseudonyms (false names) to protect the identity and the wellbeing you and your child.

What will happen to the results of the research project?

Please note that the result of the research can be published if the University sees it appropriate. If this is done you will be informed as to where you can access a copy of it. You will not be identified in the publication. If the data is being used for any additional research you will also be informed of this.

Who is organising and funding the research?

The research is totally funded by me. There are no other persons involved.

Who has ethically reviewed the project?

This project has been ethically approved via the Sheffield Faculty of Social Sciences Education department's ethics review procedure. Additionally, the University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

Will I be recorded, and how will the recorded media be used?

For this research you will be asked to be audio (voice) recorded (not video). The audio recordings of your activities made during this research will be used only for analysis or for illustration in conference presentations. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

The interview

The interview will be conducted at a time and place suitable for you, preferably in a location that is quiet with minimal distractions and which is comfortable. I will have a few guided questions, but you will be given the opportunity to speak and express your views however you like. I will be prepared to answer any of our questions or clarify anything you want. However, there may be certain areas I will be focusing on and I will apprise you of that. You will be free to decline answer if you feel uncomfortable. To give an idea, some of the area I will focus on are:

- a. Education of your child
- b. Social life
- c. Family support
- d. Government support
- e. Impact on your mental well being
- f. Experiences in caring for your child
- g. Your views on or understanding of disability

Contact for further information

If you require further information regarding the research, you can contact:

Student - Researcher:

Judy D. Taklalsingh

868 685 3947.

edp11dit@sheffield.ac.uk or jsingh68@hotmail.com

Dissertation Supervisor:

Dr. Themesa Neckles

Email: themesa.neckles@sheffield.ac.uk

For Your Records

You will be given a copy of this sheet as well as a signed copy of the consent form to keep for your records.

Thank You

Finally, I would like to express my sincere appreciation and thanks to you for agreeing to participate in this project and I look forward to working with you to address the issue of disability in Trinidad and Tobago.

.....

Judy D. Taklalsingh

Student Researcher

7.2 Appendix II Participant's Consent Form



Research Project Title:

Understanding the Perceptions and Lived Experiences of Three Mothers' Caring for and Educating Children with Disabilities in Trinidad and Tobago

Name of Researcher: Dhanmatee Judy Taklalsingh

Please initial box

I confirm that I have read and understand the information sheet dated explaining the above research project and I have had the opportunity to ask questions about the project.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

I understand that my responses will be kept strictly confidential.
I give permission for the researcher to have access to my anonymised responses.

I understand that my name will not be linked with the research materials, and I will not identified or identifiable in the report or reports that result from the research.

I agree for the data collected from me to be used in future research

I agree to take part in the above research project.

Name of Participant	Date	Signature
<i>To be signed and dated in presence of the participant</i>		

Researcher	Date	Signature
<i>To be signed and dated in presence of the participant</i>		



7.3 *Appendix III Ethics Approval To Conduct The Study*

Downloaded: 08/05/2021
Approved: 28/07/2015
Dhanmatee Taklalsingh
Registration number: 110273574
School of Education
Programme: EDUR29 Doctor of Education (EdD) Caribbean

Dear Dhanmatee

PROJECT TITLE: Mothers Perceptions and Lived Experiences of Caring for a differently-abled Child: Implications for Inclusion in Trinidad and Tobago

APPLICATION: Reference Number 005739

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 28/07/2015 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

University research ethics application form 005739 (form submission date: 21/07/2015); (expected project end date: 15/12/2016).

Participant information sheet 1010743 version 3 (21/07/2015).

Participant consent form 1010745 version 2 (21/07/2015).

The following optional amendments were suggested:

Given the vulnerability of the participants and the sensitivity of the subject matter, the researcher will need to demonstrate great care at the following points:

- 1) in gaining consent i.e. participants should feel able to say 'no';
- 2) at the point of data collection - great care should be taken in order to avoid directing the participants in any way;
- 3) when representing the accounts - take steps to ensure that accounts will not enable participants to be identified;
- 4) in the conclusions - these will be at the level of 'interpretation' rather than 'findings.'

If during the course of the project, you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

David Hyatt
Ethics Administrator
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

The project must abide by the University's Research Ethics Policy:

<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>

The project must abide by the University's Good Research & Innovation Practices Policy:

https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf

The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.

The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.

The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements

7.4 Appendix IV: List of Interview Guided Questions

These were some pre-planned questions for the interviews. However, as I engaged in doing unstructured interviews these questions acted only as a guide as participants proceeded to tell their stories uninhabited and sometimes not adhering to specifically answering the questions. Each interview lasted between sixty to ninety minutes.

1. What are your thought about disability?
2. How did you school your child?
3. How do you cope as a single mother? (for single mothers)
4. What services you accessed from the government or did you receive any support or grants?
5. How were you assisted by family members?
6. What do you think about the education system for disabled children?
7. Do you mind telling me about your social life?
8. What do you think can be done to improve the situation for disabled children in Trinidad and Tobago?

7.5 Appendix V : Process of Coding and Generating Themes

Extracts from the participants' verbatim showing the organization of data and the coding process to generate themes.

Table 3: Verbatim- Participant 1

CODES	ANA'S TRANSCRIPTION
<p>Advocacy</p> <p>Government's role</p> <p>Awareness</p> <p>Labelling/ Ignoring disability Exclusion/ Accessing services</p> <p>Trust in people to care for child</p> <p>Role of mothers</p> <p>Appropriate care services</p> <p>Qualities required to care and trust others</p> <p>Inaccessibility to services</p>	<p>Ana</p> <p>I thought the former administration would have done something given the fact that the Prime Minister has an autistic grandson but, because, I guess because they could pay for his services...ah, it wasn't a priority for them, so I think if she had made it more... prevalent...more...like the public knew then, that's okay, this is the reason why we are going forward with Special Ed Schools with Special Ed training for teachers, but I guess, because...as with physical disability in this country, mental and developmental disabilities are pushed behind a closed door.</p> <p>People don't talk about it; when people don't see it. Even when people see my son, and he starts to talk or if he gets fussy, people think about something is wrong with him, but they look at him funny. They never ask a question, okay, what's wrong with him? you know even a simple thing like to find somebody to cut his hair, is a task,</p> <p>Researcher - Does she charge more?</p> <p>Ana - No, no she doesn't, she doesn't charge any extra, she sets him up at a time of day that she knows she is not busy so there is not a lot of people in her shop, and she takes her time, she speaks to him she talks to him she brings a little video player so she puts something on to catch his attention, she takes her time with him, it's very rare that you would find somebody and she is not an overly educated person <i>but she is a mother herself, she is sensitive to his needs</i> she ask me the relevant questions and I told her you know, exactly what his situation is and stuff like that, before she even cut his hair the first time, but it is difficult to find simple services like that, much less educational services and medical services.</p> <p>Researcher - So what about government services?</p> <p>Ana: Government services are geared towards...ah.. the blind, or people with physical disabilities. They now starting to do government buildings with wheelchair access and stuff like that. There are a lot of places that people with physical disabilities can't get into.</p>

<p>Exclusion</p> <p>Lack of state Infrastructure</p> <p>Training</p> <p>Education</p> <p>Diagnosis</p> <p>Socialization</p>	<p>Researcher – Why do you think so?</p> <p>Ana- Because of the stigma of mentally ill, mentally challenged, physically disabled children, there are not a lot of services, there is supposed to be a programme in the education system where a child with special needs would go to a regular school but he will have an aide assigned to him. But the programme is there on paper, but there is never an aid available and then aides that are... they do have available, don't have the necessary training</p> <p>Researcher - Can you to tell me about your experience with regards to the education for Kris?</p> <p>Ana: Our challenges started very, very early. As with any other parent, you want to have your child move forward and a key to moving forward is to going to school and getting socialized and getting ready for the ABCs and the 123s of life. To find a preschool for him was a challenge because he was diagnosed with his illness when he was less than a year old and his seizures were not under control until he was about seven, he was almost seven when the seizures were under control.</p>
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Table 4: Verbatim - Participant 2

CODES	Sherma verbatim
<p>Future Survival of Child</p> <p>Financial Security</p>	<p>Sherma - I will say she is not a problem child, but I worry for her to be honest. I do worry as a mother, but if I worry, as Joyce Meyers...I listen to Joyce Meyers every day to get courage, its better you not worry. When that bridge reach, whatever happens will happen, and I have secured Val's financially, Judy. Right, this apartment where we here, one, one of the rent for her, is for her every month, if I'm not here to support her.</p> <p>Researcher –So she is well... her future is well supported?</p>
<p>Mothers Fear / Death/ Future</p>	<p>Sherma – It is, I know she will...I feel, however I feel, if I die Val will die shortly after me, I am just telling you that, that is how I feel as a mother, because since [her father] died she sleeps with me. Since he died I have nobody to be close to</p> <p>Researcher – That's her father?</p>
<p>Managing Behaviour</p> <p>Psychological Stress/ Trauma</p> <p>Mother's Anger/stress Self-Control</p>	<p>Sherma – She sleeps with me and we get along good, sometimes she gets angry with me as you know, when the father died, but I know I went to a psychologist when he died for her behaviour, she used to tell me things like “Daddy will haunt me” and “don't go there, and don't come”. But she told me again, it was because of the father's death, and other things happened like that, so. I used to get very angry but, I cool myself just for her.</p> <p>Researcher – I understand now. In Trinidad and Tobago, having a child like that...</p>
<p>Difficulty in Parenting</p>	<p>Sherma – Is very difficult...</p> <p>Researcher – I want you just to tell me your experience with trying to access education services</p>
<p>Difficulty in Schooling</p>	<p>Sherma – Very hard...</p> <p>Researcher – What you think about education, you know about the programmes the government has?</p>
<p>Inaccessibility of services</p>	<p>Sherma – It has nothing, it has nothing, I am telling you, in our days it had nothing for Val</p> <p>Researcher – How old is Val by the way?</p> <p>Sherma – Val is forty...</p> <p>Researcher – Right</p>
<p>Affordability for Education</p>	

<p>Home Schooling</p> <p>Psychological Impact / resilience</p>	<p>Sherma – Right, and if we had things that I could...look I send her to a paid school, I could have afford, but if a parent can't afford what will they do?</p> <p>Researcher – That's right</p> <p>Sherma– And we teach her every day, she learn, she... I mean she is very literate, very, very literate, yes she is little bit with her speech and thing little tardy, but you...I manage all of that, because I give myself courage Judy, as a parent</p>
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Table 5: Verbatim- Participant 3

CODES	PRABHA'S VERBATIM
Governments Role	<p>Prabha – But the government not doing anything about the children</p> <p>Researcher– Exactly, so what I want to know... and why, I chose to do mothers, is because for me, I feel they are the main caregiver of their children. I am a mother as well...</p>
Sympathy/pity for disabled children	<p>Prabha – Yes, and is really, really difficult to see about, because Sunday I went to a thanksgiving and it had this, a little baby, I'm telling you, and she now had a year and something, and she couldn't hear, she couldn't talk and it was really, really touching when I see this little baby... you know</p> <p>Researcher– Reminded you of your daughter?</p>
Struggles faced at diagnosis	<p>Prabha – It was really, really hard</p> <p>Researcher– What I wanted to find out though, when your child was born and how you felt, what happened?</p>
Challenges in caring	<p>Prabha – Yes, that's the only daughter I have, then she father come and die when she was four years, and from there it was really hard for me to cope. Then to see about my daughter and then to maintain my daughter and then to carry she to school. When she going to school I used to have to go in school and stay.</p> <p>Researcher– – When did you found out she had a problem? As soon as she born?</p>
Psychological Trauma/ mental anguish	<p>Prabha – When I found out she had a problem I couldn't eat, I couldn't sleep, I couldn't do anything, I felt so sorry for her, I used to cry, day and night.”</p> <p>Researcher– – How old was she? At birth?</p>
-Diagnosis / birth impairment	<p>Prabha – Well when she born she was active, playing...everything, but I don't know, when we carry she back to the Doctor and thing, well the Doctor say she couldn't hear, she couldn't talk.</p> <p>Prabha – I had to look for milk, I had to look for pampers and you know she couldn't talk and hear, she never used to stay with nobody, if I have to go somewhere, I have to go toilet, and anything I have to do, I have to tote this child with me. It was really, really hard.</p>
No support	<p>Researcher– Did you at all have support for her... like if you had to go out anywhere, somewhere to leave her? Like your parents, your sisters, brothers, or your mother?</p> <p>Interviewee – No, nobody. Nobody she stay with.</p>

<p>Understanding specific disability. Psychological impact/maternal responsibility</p>	<p>Researcher– Because she couldn't communicate? Why you think?</p> <p>Prabha – no. because If you...when she was small and thing, and say you give Kate something, she used to make sure she smell it... know what to do with it, that's how she used to carry on when she was a baby. She never... even though somebody give she something, she smell it, throw it away because she never take nothing from nobody, because how she couldn't hear and couldn't talk she feel somebody go do she something or, poison she or...</p>
<p>Distrust of others to care for child</p> <p>Maternal Efficacy</p>	<p>Researcher– But remember she was a little girl at the time...I mean when she was three...four, you never left her with anybody else?</p> <p>Prabha – No, never...never...never left that child with anybody, even in school, when we go to school, I used to stay in the morning, the teacher used to let me stay in the morning...</p> <p>Researcher– So tell me...how did she started going to school, because I'm very interested in how you started to educate her... because I know now she can read and write.</p>
<p>Sacrifices</p>	<p>Prabha – From as soon as she father died, I started sending she to school. The first school she went to was in Port of Spain. right. It have a girl, she had a son from, so she used to wait for me at, we used to go and spend the whole day in school.</p> <p>Researcher– Oh, you used to stay all day?</p>
<p>Financial/ psychological burden of care</p> <p>no support</p> <p>Time and effort/sacrifice</p>	<p>Prabha – Yes, the school, then they send we to a school in Point, but the Point school was \$500.00, so I couldn't afford to pay that. Then I went to get the public assistance. Well when I get the public assistance, it just help my travelling sometime, because the money used to never be enough. She used to go to school Cara Jeff school, well in there, we used to stay in school and all, I used to stay whole day. I do without underwear, without clothes, without food, beg people for a dollar and two dollars, to travel to reach Cara, to travel to reach South, for this child to go to school, to make she self somebody.</p> <p>Researcher– Why was that aspect so important to you?</p>
<p>Stigma/ worry for the future/ importance of education</p>	<p>Prabha – Yeah, because it was very important for a child like that child, to make sure, nobody, when they grow up that nobody can take advantage of them, they know to read, they know to write, they have they own sense that no disability so nobody can't take advantage on them</p>

7.6 Appendix V - Excerpts - Coded Data by Category

Table 6: Code Category Example: Accessing Services

Ana	Prabha	Sherma
<p>So we found somebody years ago, that she takes her time with him just to cut his hair, but it is difficult to find simple services like that, much less educational services and medical services.</p> <p>Government services are geared towards... the blind, people with physical disabilities. But...there are a lot of places that people with physical disabilities can't get into.</p> <p>Because of the stigma of mentally ill, mentally challenged, physically disabled, disabled children, there are not a lot of services, Programme is there on paper, but there is never an Aid available in schools and then Aids that are... they do have available, don't have the necessary training to deal with these children</p> <p>Because you will think that there will be at least one place for him. Nothing was available and I wondered to myself, what do parents do? Where do you go? Who do you turn to? Who do you ask to point you in the right direction.</p> <p>A lot of parents, especially low income parents, who</p>	<p>Then they send we to a school in Point , but the Point school was \$500.00, so I couldn't afford to pay that. Then I went to get the public assistance, well when I get the public assistance, I just help meh travelling sometime eh, because the money used to never be enough. She used to go to school Cara school, well in there we used to stay in school and all, I used to stay whole day</p> <p>I had it really, really hard, we had to go to Court, and then we went to the Legal Aid right up the road, she real help we, she help we get through to High Court, Family Court in Port of Spain, so it was real hard, real real hard</p> <p>Well he, (the prime minister) don't look up on them children them.</p> <p>I think none of them don't work on them children yeah, nobody don't really help...</p> <p>I find they should have something to help, because, during the week, it have this teacher from Port of Spain, and it was real sad how she was talking to these children and how nobody don't care about them.</p>	<p>Well...I think, nowadays because I read every day, and I know there are lots of things now on stream, Judy for parents, like my child, they have a lot more than when my child was born, and I think that is a good start, a starting point in life,</p> <p>It have nothing, it has nothing, I am telling you, in our days it had nothing for Val</p> <p>I feel Judy, between me and you, if Val had the right education place to move her up she would have been better off than how she is today</p> <p>But in my days it was nothing, nothing, nothing. So that is why it was more difficult for me but I manage, and I think I did a good job, I like to-they say self-praise is no praise, but Judy, I find I did a lot of good things for my child.</p>

<p>are not well educated ...they won't know where to turn, because there are no services available to help them progress,</p> <p>As with Educational services, Medical services were not available for my son.</p>	<p>Nobody don't give them a job. Do you know how much application, when my daughter finish school you know how much application she send? And when in the interview when they hear she can't hear, she can't talk then no where she didn't get no job.</p>	
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7.7 Appendix VI: : Iterations of Coding to Generate Themes

Table 6: Iterations and Themes

First Iteration	Second Iteration	Third Iteration	Fourth Iteration
57 Codes Identified	29 Broad Headings	12 Themes	3 Final Themes
<ol style="list-style-type: none"> 1. Access to education 2. Access to services 3. Advocacy 4. Attributes of children 5. Being normal 6. Blessing 7. Change in life priorities 8. Expense 9. Characteristics of child 10. Concessions made for children 11. Death 12. Denial of disability 13. Dependency 14. Desperation 15. Diagnosis and coping 16. Difficulty in parenting 17. Educational training 18. Employment 19. Equal opportunity 20. Exclusion 21. Expectation 22. Forming relationships 23. Government role 24. Guilt 25. Happy 26. Home schooled 27. Illness 28. Imperfect vs a blessing 29. Labelling 	<ol style="list-style-type: none"> 1. Adjustment 2. Advocacy 3. Blessings 4. Diagnosis 5. Education 6. Employment 7. Home school 8. Equality 9. Exclusion 10. Future survival 11. Government role 12. Happiness 13. Illness 14. Isolation 15. Mental stress /trauma 16. Multiple roles 17. Normal 18. People's perceptions 19. Pride 20. Protection/owner 21. Religion/ beliefs 22. Sacrifice 23. Shame 24. Social life 25. Sorrow 26. Socialization of child 27. Spouse support 28. Stigma/ blame/guilt 29. The types of disability 	<ol style="list-style-type: none"> 1. Diagnosis 2. Preparedness 3. Happiness 4. Mother's Roles 5. Responsibility 6. Normal /exclusion 7. Support 8. Government roles 9. Maternal efficacy 10. Cause of disability 11. Protection 12. Stigma 	<ol style="list-style-type: none"> 1. Preparedness 2. Maternal Responsibility 3. Social Support

30. Lack of infrastructure 31. Low income 32. Mother as teacher 33. Mothers' lives revolves around child 34. Mothers' blame 35. Multiple role of mothers 36. On constant call 37. Peoples' perceptions 38. Pride 39. No Preparation or knowledge of disability 40. Pity /sadness /sorrow 41. Protection 42. Public awareness 43. Relatives -lack of support 44. Religion-Karma 45. Sacrifice 46. Schooling 47. Shame 48. Simple lifestyle 49. Social life 50. Socialization for child 51. Specific type of care 52. Stigma 53. Superstitions 54. Support from spouse 55. Survival skills 56. Sympathy 57. Trust			
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