**Perception, knowledge and experience of caregivers supporting Autistic individuals or persons that may be Autistic in Grenada: An Exploratory Study.**

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March 17, 2020.

This thesis is  submitted in partial fulfilment of the requirements for the degree Of Doctor of Philosophy in Education and Social Justice.

Department of Educational Research,
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This thesis results entirely from my own work and has not been offered previously for any other degree or diploma.

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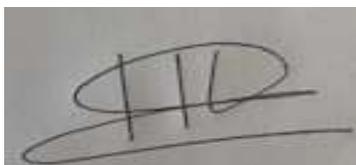


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## Abstract

The literature suggests that the complexity of Autism Spectrum (AS) and the multidimensional care needs of Autistic individuals, often require the involvement of family and caregivers to help with providing support and advocating for an improved quality of life for the person on the spectrum and their family. This involvement in the life of the autistic person can be an enriching and at times challenging and stressful experiences for families and caregivers. To this end, this thesis explores the perception, knowledge and experience of caregivers supporting Autistic individuals or persons that may be Autistic in Grenada. To date, most of the research on autism has been conducted in developed and English speaking countries where there is extensive professional support and services. There is a dearth of research on the prevalence, identification and experiences of people living with autism and their caregivers in non-Western, less affluent and developing countries like Grenada.

A sample of 15 caregivers supporting Autistic individuals or persons that may be Autistic participated in this study. A narrative ethnography approach was used, including a semi-structured narrative interview supported by interview observation. This qualitative methodology seemed most appropriate to capture and reflect the indigenous account on the perception, knowledge and experience about autism from Grenadian caregivers. This study makes an original contribution to the field as the primary research exploring the lived realities of caregivers in Grenada supporting Autistic individuals or persons that

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may be Autistic and also contributes culturally contextual and empirical knowledge to the literature. Four themes that emerged from the synthesis of the research finding include 1 perception of autism; 2 thoughts on the caregiving role/task; 3 supporting the supporter, 4 barriers to assistance and 5 support; and, aspiration, expectations and ideas. Each theme has associated subcategories that are discussed in turn to elucidate the caregiver's understandings and lived realities supporting an autistic person or someone that maybe autistic. This research has implications for practice and policy development directed towards reducing stigma and exclusion of autistic people and their caregiver. This research can also provide education to caregivers and the Grenadian public on the cause of autism spectrum disorder and addressing meaningful supports for the person on the spectrum and their caregiver.

# Contents

# **Acknowledgements**

## List of abbreviations

Example:

ASD             Autism Spectrum Disorder


AOP             Anti Oppressive Practice


AS              Asperger Syndrome


ABA             Applied Behaviour Analysis

## List of Figures and Tables

# Chapter 1: Introduction

## 1.1 The Focus of the Research

This thesis is concerned with exploring the lived experiences of caregivers supporting an autistic individual in Grenada. For this research, a caregiver is related to anyone (parent, relatives and friends) within the Grenadian cultural context who is providing primary care or who is most responsible for the autistic person or the person that may be autistic. This is a relatively small, discrete group of caregivers who are poorly understood and under researched. It is, however, an important field for educators, helping professionals and researchers to consider for several reasons, which are outlined below.

## 1.2 Statement of the Problem

There is a growing body of research literature related to Autism diagnoses, intervention and treatment, but few studies focus on Autistic individuals and their families within the Caribbean region. The available data come from studies on early identification, early intervention and treatment in Aruba (Balkom, et al., 2009); on maternal and paternal age and the relation to the risk for autism in Jamaica and Aruba respectively (Rahbar, et al., 2012; Balkom, et al., 2012); on public awareness of autism in Jamaica (Pottinger, 1998); on childhood autism disability prevalence in Barbados (Holder,1999); a descriptive/ comparative study on the positive impact of autism on families in Barbados, Jamaica and Florida (Holder, 2013); and Alleyne, (2016) reported on the current status of autism across the Anglophone Caribbean. Indeed, Grenada is in its infancy in terms of increasing awareness and understanding of Autism Spectrum (AS) and in advocating for autistic individuals and families. Understanding the caregiver experiences of supporting an autistic individual is crucial in providing support, raising awareness, providing education and in developing the services that are urgently in need of in Grenada.

## 1.3 Scope of the Study

A scoping review of the literature offers several perspective and critique on the definitions of disability and on a range of models and theories within the field of disability studies as well as within the social and political movement of disabled people. The four broad models identified within the literature are the medical model, the social model, the human rights model, and the Critical Disability model (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). Each of these models has potential strengths and possible limitations with respect to knowledge production, inclusivity and representation of the diverse needs and experiences of people.

Undeniably, the disability discourse is shifting and has surpassed disciplinary and geographical boundaries towards the social, economic, psychological and cultural needs of individuals and communities (Goodley, 2013). However, the epistemological underpinnings of these disability models and theories are deeply connected to Eurocentric perspectives, which privilege theories from the global North (Meekosha, 2011). It is possible that these theories from the global North may not fully recognize and respond to the complex needs and experiences of the cultural, religious and indigenous practices that shape the meaning of disability in the global South, including places like Grenada.

In this study I offer a contextual account of the assumptions underpinning a few of these models or conceptual framework for autism. I decided to focus on the theories that are most dominant within the autism literature (medical model, social model and neurodiversity (details in Chapter 2). Reflecting on the challenges of the disability discourse in relation to Northern epistemologies, where possible, I provide culturally contextual knowledge, practice and indigenous ways of knowing about disability. Furthermore, narrative inquiry is used in this research as an acknowledged alternative and/or to counter the dominant and western narratives around disability and autism in particular. The stories people share are not only personal but they are also social and culture. Smith & Sparkes, 2008 suggest that "studying narrative is valuable for what

they reveal about socio-cultural life, in that society and culture 'speak themselves' through an individual's story" (p.18). Narrative is particularly useful for disability studies in that it gives insight into a person's thoughts, feelings, behaviours and identity and the influence time, space, location and organization can have on shaping (constrain and/or enable) that individual's capabilities to flourish. As Smith & Sparkers, (2008) stressed "the body is a storyteller, and it is partly through the tales it tells what we may interpret, giving meaning to and understand bodies" (p.19). This is not to deny the biomedical realities of impairments, the fundamental human rights of persons with disabilities, the experiences of exclusion, social oppression and intersectionality that people living with disabilities and their families may experience. However, for this exploratory research, I suggest that narrative is a valuable and useful place to start to both contextualize and theorize the participants' experiences. It was important that the participants in this study construct their own stories of inclusion and/or exclusion through reflecting on their lifestyle, relationship, community and collective experiences as caregivers supporting an autistic individual or someone who maybe autistic within the socio-economic context in Grenada. The caregivers sharing their experiences may challenge Northern epistemologies and might encourage the decolonizing of disability discourse on the island (details in Chapter 4).

## 1.4 Research Question

The overarching goal of this study was to explore caregivers' perceptions, knowledge and experiences supporting autistic individuals within the Grenadian social context. The thesis was underpinned by the following research questions:

1. What are the lived experiences of caregivers supporting Autistic individuals and/or persons that may be Autistic in Grenada?
2. How do caregivers supporting Autistic individuals and/or persons that may be Autistic conceptualize these experiences?
3. How do caregivers learn to become well-informed to support Autistic individuals and/or persons that may be Autistic in Grenada?

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4. What further support do caregivers identify they need?

5. What recommendations would caregivers supporting Autistic individuals and/or persons that may be Autistic suggest is needed to improve the quality of life for themselves and the autistic person?

## 1.5 Significance of Study

The research aims:

1: This study can broaden academic discourses and contribute to the literature by providing empirical knowledge that focuses on the realities of caregivers of autistic persons living in Grenada. 2: Highlighting and analyzing the specific experiences and stories of the study participants can contribute to the conversation around the learning, care practices and supports for individuals assisting people on the autism spectrum. 3: The research can contribute to autism education and awareness- a beneficial outcome for people on the spectrum, their families and the society. 4: The research can encourage further discussion on the experiences of autistic persons living within the wider Caribbean region and further the cultural conceptualization of autism. 5: Deploying autism research in low resource non- Western countries like Grenada can extend autism research globally and address questions (cultural -socioeconomic) to reflect the needs and experiences of the autism population worldwide.

## 1.6 Organization of Study

The study is structured into five distinct chapters.

Chapter 1: Introduction - In this chapter, I provide the focus of the research, statement of problem (autism & caregiver experience in the context of Grenada). I provide a discussion on the scope of the research. I also highlight the key research questions, the significance of the study and the organization of the thesis.

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Chapter 2: Literature Review- In this chapter, I review the literature. I provide an understanding of autism from three distinct perspectives. I then provide context on the intersections of culture and autism, inclusive of the influence on diagnosis and treatment decisions. From there, I go on to consider the lived realities of caregivers. The final section considers the gap that is evident in the literature.

Chapter 3: Methodology- Outlines the purpose and location of the study, followed by the context of the study. I then outline the ontological and epistemological stance of the research. I outline the qualitative methods that I utilized in this study including the research design, and an explanation of narrative reality. This is then followed by a discussion on the recruitment and procedure processes. I offer detailed narrative descriptors of each participant in the study, followed by a detailed explanation of the data collection method inclusive of semi-structured interviews and field observation. The chapter offers insights into the analysis of the data, the role of self-reflexivity and finally the ethical consideration in the study.

Chapter 4: Findings – In light of evidence (primary data) collected via the interviews and observation, the chapter detail the findings of the research in relation to the research questions outlined in the methodology section. The findings will be presented and supported by extensive use of direct quotations from the caregivers in the study.

Chapter 5: Discussions and Conclusion- This chapter describes and analyzes what can be learnt from the information generated. The findings presented using appropriate structure, and concerning the overarching research questions where possible, the findings from this study will be related to those of similar studies. Additionally, reflections, limitations and future direction will be discussed. Implications for further research will be discussed including the study's limitation. This is followed by a range of implications that the findings of this study could have for improving policy and practice on the Tri Island

nation.  Finally, I offer a conclusion on the experience of caregivers supporting someone living with and/or suspected of ASD in Grenada.


## 1.7 Position

My motivation for this research is partly personal and partly professional. The personal part of my interest is related to the exclusion and stigma that I have observed towards relatives and friends who experienced mental health challenges and other disabilities, including autism, although undiagnosed. These exclusionary experiences made me uncomfortable, as I firmly believe that everyone (including those that are differently-abled) should be treated with respect and dignity. This brings me directly to the professional part of my motivation, which is connected to my career as a clinical social worker in a Neurodevelopmental program at a hospital in Toronto. These influences, both personal and professional brought me to my studies in education and social justice. Additionally, I have always had a special interest in the experiences around autism and intersectionality with culture in Grenada. The result of these motivations are this dissertation.

Reflecting further on my personal experience, I can share that my understanding of autism when I lived in Grenada was severely limited.  I did not have language or context to make meaningful sense of an autistic's person presentations, which I inadvertently referred to as bizarre and odd. At that time, my understanding of autism and more generally around disabilities was informed by a worldview that has been shaped by the social and cultural practices in Grenada. For instance, as a teenager when I misbehaved I can recall being threatened by my parents that they were going to send me to the "pink house" which was an institution for those living with mental health challenges. I recall other moments when there were threats to relocate me to a relatives' house to ensure my alignment to expected norms or to encouragegood behavior. I was fearful of this relative and now I suspect that he may have been on the autism spectrum given his restricted and repetitive behaviours. Therefore, while I recognized the need for inclusion and respect for

all peoples, my entry point to this discourse has been challenging and created moments of tension and internal confusion.

Once I migrated to Canada, I became much more interested and invested in the affairs of autistic people and their caregivers and began working professionally with the community? This has given me much context and perspective on the lived realities of autistic people and their caregivers, my worldview now being more expansive.  To this end, and although I work within a program/ hospital prescribed clinical understanding of autism, I view it differently. I do not view autism as a disorder that needs to be fixed. Instead, I acknowledge that autism is a normal and natural human variation and is more closely connected to the socially constructed and neurodiversity perspective (see sections 2.1.2 & 2.1.3) for details. Having said that, I do believe there is value in considering clinical perspectives and evidence outcomes, especially concerning effective and meaningful support geared towards improvement in the quality of life for the autistic person and their caregivers.

As a side note, and as demonstrated above, it has become suitable in research papers to use person-first language, describing what a person has, not what a person is. For example, to write "autistic" or autistic person instead of "individual living with autism."  For this research, I will mostly be using person-first terminology to enhance sensitivity and to reduce insensitivity and stigma that has historically labelled people with disabilities. Further, as a clinician and researcher trained in anti-oppressive social work practice (AOP), the person's first language connects well with AOP theory as it challenges the marginalization of people with disabilities by addressing language that can be oppressive in the form of ableism.  At certain points in the thesis, I will use the terms "ASD," "autism," and "on the spectrum" these are representations of the range of the "diagnoses" characteristics that the current definition and the literature of autism encompasses.

# Chapter 2: Literature Review

## 2.1 Overview

In this section, I will draw on the relevant literature and will provide a conceptual framework for Autism research and practice, first, from a medical or clinical standpoint, then, from a socially constructed perspective, followed by a neurodiversity standpoint. The cultural perception of disability will be explored with a focus on autism. Further, I will examine the intersections of culture and autism on prevalence rate, etiology, diagnostic and treatment processes to help conceptualize these experiences. Families and caregivers respond to Autism Spectrum Disorder (ASD) diagnosis differently, given their cultural and racial background. Therefore, I will consider adjustment experiences as well as coping strategies of caregivers, generally with specific inferences from across diverse cultural groups. For the purpose of this review, I will rely on a broad definition of culture and the related proxies inclusive of nationality, race, or ethnicity (Brown & Rogers, 1997).

### 2.1.1 Autism: As an evolving concept & Clinical Perspective

The concept and definition of autism and, subsequently, its diagnostic criteria, treatment, and characterization, continue to evolve from its inception (Constantino & Charman, 2016). Recent evidence-based research, socio-political and cultural shifts continue to influence the understanding of the Autism Spectrum Disorder (ASD), including the support systems, education and treatment practices offered to individuals on the spectrum and their families (Anagnostou et al., 2014; Wolff & Hawes, 1995). The term autism was first used in the early 1900s by a Swiss psychiatrist Eugen Bleuler and was associated with schizophrenic symptoms and presentations (Bernier & Gerdts, 2010). This idea of autism as early childhood schizophrenia continued and became even more pervasive in the 1950s and 1960s, and was linked to an initial presentation of emotional disturbance rooted in the child's parents' characteristics (Berney, 2000; Evans, 2013). In other words parents, mothers,

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in particular, were held responsible for their child's behavioural presentation. It was not until the 1970s that these ideologies were disproved (Baker, 2013). At that time, there was still no consistent definition of Autism. However, there was a paradigm shift towards a more biological understanding of the disorder distinct from what was considered to be "mental retardation" currently and more appropriately referred to as mental illness and other psychogenic presentations (Mintz, 2016).

It is argued that some of the most significant contributions to our understanding of Autism come from individual clinicians and researchers (Howlin, Charman, & Ghaziuddin, 2014; Wolff & Hawes, 1995). Chief of these is psychiatrist, Leo Kanner, and pediatrician, Hans Asperger. In his published paper "Autistic Disturbances of Affective Contact" (Kanner, 1943), Kanner explained the behavioural presentation of several children he studied, whom he claimed presented with "extreme autistic aloneness," "delayed echolalia" and an "anxiously obsessive desire for the maintenance of sameness" (p.242). Kanner, (1943) added that many of these children had extraordinary memory skills. Kanner will later refer to this condition as "early infantile autism" (Kanner, 1944).

Similarly, in 1944, Hans Asperger described the patterns of behaviour and abilities of four boys in his study. He noted that the patterns and behaviours included; "lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest and clumsy movements" (Attwood, 1998 p.11). He called these behaviours and abilities "autistic psychopathy." Although there is some variation in the description and conceptualization of the disorder between Leo Kanner and Hans Asperger, essentially, they both described the same condition, and both provided an exceptional clinical foundation for continued autism research and practice. However, it was Lorna Wing who coined the term "autistic spectrum disorder" and categorized the triad of behavioural impairment of the disorder (Wing, 1981). The traditional triad of behavioural impairments in autism disorder includes; difficulty with communication, difficulty with behaviour or social interaction and difficulty with social skills.

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For the first time in 1980, autism appeared as a separate category in the American Psychiatric Association's Diagnosis and Statistical Manual of Mental Disorders (DSM-III). Indeed, the DSM is the primary diagnostic referenced guide used by clinicians in North America to formally diagnose autism and related disorders (American Psychiatric Association, 2013; Regier, Kuhl, & Kupfer, 2013). DSM-III provided a list of three objective criteria for diagnosing autism separate and distinct from schizophrenia. These include 1: "lack of responsiveness to other people," 2: "gross impairment in communicative skills" and 3: "bizarre responses to various aspects of the environment, all developing within the first 30 months of age" (American Psychiatric Association, 1980).

Researchers and autism advocates felt that the DSM-III criteria were too restrictive and campaigned for more comprehensive diagnostic flexibility and expansion (Barker, 2013). Subsequently, in a revised DSM-III-R (1987), the age at onset requirement for autism was removed and a new category "Pervasive Developmental Disorder, Not Otherwise Specified" (PDD-NOS), was added for those individuals meeting some but not all of the diagnostic criteria previously outlined for an autistic disorder.

In 1994 and 2000, with language more inclusive than its predecessor, the DSM-IV, and DSM-IV-TR respectively were introduced with further modification to the diagnostic criteria for autistic disorder (American Psychiatric Association, 1994; American Psychiatric Association, 2000). Additionally, the Pervasive Developmental Disorder-Not Otherwise Specified category expanded to include five subtypes: Autistic disorder, Asperger disorder, Rett disorder (Rett syndrome: RTT), Childhood disintegrative disorder, and PDD not otherwise specified (PDD-NOS), (Volkmar & Reichow, 2013). For the first time, Asperger's disorder, sometimes referred to as high functioning autism was added to the DSM to capture individuals who presented with less severe communicative symptoms such as language delay but significant deficit with social interaction (e.g the inability to develop meaningful and age-appropriate relationships) and the preoccupation with one or more stereotyped and

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restricted pattern of behaviours (American Psychiatric Association,1994; Toth & King, 2008).

The expansion of the autism definition and diagnostic criteria has undoubtedly created a challenge for researchers, professionals, families, and individuals living with the disorder (Volkmar & Reichow, 2013). The vast versatility and range of social and cognitive capabilities, as well as the related genetic and neurological conditions amongst those with an autistic disorder diagnosis, makes it difficult to determine the most effective treatment and support (Reichow & Volkmar, 2009). Nonetheless, the expansion of the definition and criteria of the syndrome has provided the opportunity for more families and individuals to receive the diagnosis, which is often required to access autism-specific programs and services (Austim Speaks, 2016).

The debate on the conceptualization of autism and the diagnostic criteria is ongoing. Although the recent release of the DSM V was intended to provide a more rigorous definition of the disorder informed by research, analysis and professional opinion, these recent changes, however, have added to the continuing controversy or even "hostility" as legitimate concerns have been raised about the impact on people on the spectrum and their families (Fitzgerald, 2012). For instance, in contrast to the DSM-IV & DSM-IV-TR respectively, the DSM-V subsumed autistic disorder, Asperger disorder, Rett disorder (Rett syndrome: RTT), childhood disintegrative disorder, and PDD not otherwise specified (PDD-NOS) into an umbrella term called autism spectrum disorder (ASD). With the removal of Asperger's disorder, some individuals and their caregivers are concerned that access to much-needed services will become more difficult.

Another change that some individuals find contentious is about the diagnostic descriptors and symptomatic characteristics for autism, shifting from three to two criteria (Mandy, Charman, & Skuse, 2012). This means a person that may be autistic must meet all three behavioural conditions in social interaction, communication, restricted repetitive & stereotyped patterns of behaviour

category (first criteria), and at minimum two conditions in the restricted, repetitive behaviour, interests, and activities category (second criteria) (American Psychiatric Association, 2013). These presentations must be present in early childhood, and there must be no evidence of conditions/ disorders that are similar to ASD, and the symptoms present must cause clinically significant impairment in social, occupational, or any other area of functioning (American Psychiatric Association, 2013). Researchers and families argue that these changes make it much more challenging to receive an ASD diagnosis much needed to access professional and social supports, particularly in western cultures (Frances, 2013).

To conclude, the notion of autism has been a fluid concept that has continually evolved in the definition and diagnostic criteria. The prevailing trend within the literature and emerging scientific research seem to suggest an approach that is grounded within the medical framework and on clinical presentation. Indeed, this conceptualization has provided beneficial information to inform policy development, clinical formulation and intervention and service provision for individuals and families living with ASD. For instance, with advanced diagnostic testing such as Chromosomal microarray analysis (CMA), a technology used for the detection of clinically-significant microdeletions or duplications chromosomal and genetic conditions (Xu, Mitchell, Richman, & Clawson, 2016). In the Global North, with the use of CMA technology, individuals and caregivers are provided valuable information on the disorder and the best option for treatment or therapy based on the genetic results (Xu, Mitchell, Richman, & Clawson, 2016). Indeed, genetic microarray analysis has implications on early diagnosis, early intervention and treatment outcomes for persons on the spectrum and their caregivers. It should be noted that the DSM and other mental health nosology are likely produced in developed high-income countries and may have problematic implications for low and middle-income countries in the global south whose access to resources and lived realities are different. With this historical and clinical account of the disorder in mind, I will now consider a counter-narrative of autism diagnosis from a social construction

perspective as well as highlight advocate's and caregiver's perceptions from that lens.

## 2.1.2 Autism: A Socially Constructed Perspective

As has been established within the medical model, and as is evident in the Diagnosis and Statistical Manual of Mental Disorders (DSM), Autism Spectrum Disorder (ASD) is viewed as a neurologically based impairment or disorder that can affect a person's capability to carry out day to day functions (Molloy & Vasil, 2002). Within this biomedical framework, an "impairment" or a disorder is conceptualized to be a disability that requires to be treated or "fixed" to improve that individual's quality of life (Wang, 1992). In contrariety, and drawing from the social model of disability, the social constructionist approach challenges those assertions and argues that disability should not be viewed exclusively as an "impairment" or "problem" within the disable person per se but as a problem produced by the social and political structures within society that exclude (intentionally or inadvertently) and disable individuals (Anastasiou & Kauffman, 2011; Clegg, 1993). Currently, and more explicitly, alternative perspectives have been presented within the disability literature and amongst members within the autism community that contest the medical pathology with a preference for an analysis that considers the social construction of autism (Waltz, 2013).

Accordingly, an acknowledgment that ASD is socially constructed is not necessarily a denial of the genetic or biological underpinning and symptomatic presentation of the disorder; however; it is a recognition that the [changing] ideas as outlined above about autism, whether these are based on beliefs or evidence have had an ongoing impact on autistic people, their families, society in general, as well as on clinical and professional practice. Molloy & Vasil, (2002)  agreed and argued that " the social model of disability also agrees that impairments and illnesses exist in the world, but acknowledges that how these illnesses and impairments are classified, treated and interpreted is socially constructed" (p.622). In the context of Grenada this will be an important

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consideration as it is not clear how people living with disabilities including autistic individual conceptually make sense of their experiences and how the current health and education policy and social system may contribute or impede their capabilities.

Proponents of the social constructionist model argue that the medical model conceptualization of developmental disorders is problematic and counterproductive (Waltz, 2013; Molloy & Vasil, 2002). They contend that once an individual is given a diagnosis, it is possible that this diagnosis will then define the person, and it will become more challenging to appreciate the person's individuality (personality & expression) and unique capabilities as is likely that every behaviour or action by that person will be filtered through the ascribed diagnosis without considering the social context in which the person exists (Waltz, 2013).

Additionally, within the social constructionist framework, the Diagnosis and Statistical Manual of Mental Disorders (DSM) itself is seen as contentious given the many changes underwent in the classification and description of autism over the past seventy years. It is argued that these ongoing changes can be interpreted as a human construct of an issue or "disorder" that can be open to various interpretations, alternative understanding and perspective and even misuse (Volkmar & McPartland, 2014; Waltz, 2013). In other words, while the DSM provides some useful and relevant information about diagnostic classification and criteria, there remains some ambiguity about its variability and application towards its evaluative objective. For instance, about Asperger Syndrome, Wing (1981) noted nearly 40 years ago

> **As with any condition identifiable only from a pattern of abnormal behaviour, each element of which can occur in varying degrees of severity, it is possible to find people on the borderlines of Asperger Syndrome in whom the diagnosis is particularly difficult. Whereas the typical case can be recognised with ease by those with experience in the field, in practice it is found that the syndrome**

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**shades into eccentric normality, and certain other clinical pictures (p. 120).**

It is clear from Wings (1981) assertion that there is a level of subjectivity based on knowledge and experience embedded within the diagnostic process for Asperger Syndrome (AS). Indeed, the absence of consistent agreement and clearly defined structure on the classification of AS on the autism spectrum within the DSM has contributed to this conceptualization controversy. Consequently, there has been a re-framing of AS on how it should be viewed within society (Molloy & Vasil, 2002). Following the social model of disability, autism advocates, including some caregivers suggest that AS should be considered as a personality difference rather than a disorder that needs to be diagnosed and treated as outlined in the teleology of the medical model (Molloy & Vasil, 2002). Social constructionists contend a view of autism from an epistemological standpoint that is resistant to biomedical pathology that is autism is not a disease or impairment to be fixed. Social constructionism instead draw from the discourses that suggest that an individual capability to flourish can be limited by the social and political structures within our society that are inflexible and inaccessible.

Another concern by social constructionists is the vagueness of the diagnostic criteria, as noted above and the use of language in describing people on the spectrum. As a basis for this discussion about the social construction paradigm, it would be essential to decide on what normality is and against what it is being measured as well as consider the impact on the lived reality for autistic people and their families. The Proponents of the social construction of autism emphatically reject the notion of normal vs abnormal dichotomy, which they argue is an ideological construction by clinicians, professionals, and researchers that can potentially exclude people living with autism from society (Terzi, 2008).

Undeniably, Social constructionism is determined to highlight deficiencies of the biomedical model, including the negative implication for persons on the

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spectrum and their caregivers (Waltz, 2013). For instance, the use of medical language such as "abnormality," "disorder', "deficiency" and "impairment" to describe autistic people. It is argued that it contributes to the negative narrative surrounding an autism diagnosis and has broader social implications such as stigma within our societies.  As autism research and practice continue to expand, the biomedical or clinical perspective of autism may continue to be called into question as well as there might be additional perspectives on the social conceptualization. However, it will be important that both the biomedical and social constructionist perspectives critically consider the cultural contextualization of autism to ensure that supports and services for those on the spectrum and caregivers are culturally sensitive, culturally responsive and appropriate.

### 2.1.3 Autism: Neurodiversity perspective

Another conceptual framework for autism that is evident within the research literature comes from Neurodiversity or the autism rights movement. For this thesis, the neurodiversity model of autism is offered to help understand the concept of autism from a novel and fundamentally different perspective. The term "neurodiversity" is relatively new and is credited to Judy Singer a sociologist diagnosed with Asperger Syndrome (Singer,1999; Jaarsma & Welin, 2011). Neurodiversity advocates present two claims which are often interdependent. The first claim is the notion that neurological conditions (brain wiring) amongst people vary and being autistic (neurodiverse) is an example of that variance among the human population and in comparison to "normal" (neurotypical) individuals (Jaarsma & Welin, 2011). The second claim is about the inherent human rights and inclusion for all people who are neurological different (Jaarsma & Welin, 2011). In other words, and according to Kapp, Gillespie-Lynch, Sherman, & Hutman, (2013), "the neurodiversity movement seeks to provide a culture wherein autistic people feel pride in a minority group identity and provide mutual support in self-advocacy and community" (p.60). Ultimately, these self-advocates are generally concerned with celebrating their

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identity and improving the quality of life of people for those within the autistic community.

While the autism rights movement acknowledges that autism is primarily caused by biological factors they very strongly oppose the pathology within the medical model and drawing from the social model of disability, they posit that the autistic identity or autism is constructed as a disability because of the inadequate social and political infrastructures within society (Baker, 2011). Indeed a growing number of autistic people and their caregivers are open to the concept of neurodiversity as they recognize that instead of autism cure and treatment, what is needed are systems and infrastructures that are accommodating and responsive to the neurological differences for all humans within our society.

The neurodiversity movement undertaking for a society that is more socially and politically compatible for autistic people has drawn some controversy. Some suggest that the movement encourages the amelioration of autism (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). On the contrary, others disclose that the movement is opposed to diagnosis and intervention needed to ameliorate challenges (Kapp, et al. 2013). For example, the use of Applied behavioural analysis (ABA), an evidence-based teaching intervention used to reduce challenging behaviours by reinforcing desirable adaptive new behaviours and skills across environments (Medavarapu, Marella, Sangem, & Kairam, 2019). Given the broad spectrum of autism and the range of presentation and capabilities, perhaps there is space to consider both positions in the engagement of autistic people and their families/ caregivers.

An awareness of the neurodiversity conception of autism, especially as it relates to "identity politics" and the reframing of autism can potentially contribute to more positive experiences for autistic individuals, asserting themselves as different rather than defective. The neurodiversity model offers a paradigm shift from the deficit-based model towards a conceptualization of autism that is holistic, sociocultural, socio-political and inclusive of the autistic person, their

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capabilities and opportunities. Likewise, the definite autism positive stance that is embedded within the neurodiversity model can potentially foster greater respect, acceptance and inclusive practices by caregivers and society, in general, supporting people on the spectrum across cultural and geographical boundaries.

## 2.2 The intersection of culture and autism

One of the overarching questions in this research is an exploration of the caregiver experiences supporting an autistic person within the cultural context of Grenada. According to Mandell and Novak (2005), "Culture is a group of people's ways of life, consisting of predictable patterns of values, beliefs, attitudes, and behaviours which are passed down through generations" (p.110). Moreover, although culture is stable, it is also continually evolving (Matsumoto, 2007). Accordingly, culture influences our worldviews and attitudes on supports and treatment delivery practices on various health issues, including mental health and disability (Ravindran & Myers, 2011). For example, in the western hemisphere, support modalities for autism rely overwhelmingly on clinical intervention such as cognitive therapy, behavioural therapy, occupational therapy and various pharmacological approaches (Case-Smith & Arbesman, 2008: Frye, Sreenivasula, & Adams, 2011).

On the other hand, and in comparison to western society, other cultures, for example, Turkish and Asian communities may have a preference for alternative and contemporary approaches in supporting autistic people. These include interventions such as herbal medicine, nutritional supplements, diet therapy, acupuncture and spiritual healing (Levy & Hyman, 2008; Frye, Sreenivasula, & Adams, 2011; Bang, et al., 2017; Klein & Kemper, 2016). I will return to this point later in the chapter.

Communities will rely on what they believe is the best practice to improve the quality of life for individuals on the spectrum based on their knowledge within that particular cultural and socio-economic context. Indeed, culture shapes

individual and familial perception about disability in general, and on ASD etiology, conceptualization, treatment decisions and on the caregiver, healthcare provider relationships in particular (Mandell & Novak, 2005; Ennis-Cole, Durodoye, & Harris, 2013). For this reason, cultural milieu must be considered within the research and treatment approaches for autistic people and other disabilities as it would be erroneous to assume that the treatment modalities developed in the west can be generalized without modification or cultural adaptation for people on the spectrum across ethno-racial and geographic communities (Daley & Sigman, 2002). For instance, the cultural values and factors that are distinctive to the Grenadians must be considered in the development and preference of policy that supports for autistic people and their families.

### 2.2.1 Prevalence rate of autism

According to the Centers for Disease Control and Prevention (ASD, 2016) in the United States, the prevalence rate of ASD for children under eight years old is 1 in 68. In the United Kingdom, it is estimated to be at 1 in 100 children Baron-Cohen, et al., (2009), and in Canada, a recent study found that approximately 1 in 94 children has a diagnosis of ASD (Canada, 2016). These statistics suggest that a number of children and families are affected by the disorder; however, it is a representation of three prominent developed countries that are also producing extensive epidemiologic research on autism. While North American and European investigations have shown much progress concerning early detection and diagnosis, based on genetic (Abrahams & Geschwind, 2008), biological (Belmonte, 2004), developmental (Jones, Gliga, Bedford, Charman, & Johnson, 2014; Elsabbagh & Johnson, 2010) and possibly environmental factors (Currenti, 2009), of ASD, the prevalence rate as inform by the diagnosis recording amongst middle income and developing countries are still sparse resulting in an inaccurate and incomplete global perspective on rates of autism.

In international surveys, Fombonne (2005), states that the average prevalence rate of ASD is estimated to be 13 per 10,000 for autistic disorder, 21 per 10,000 for pervasive developmental disorders not otherwise specified, and 2.6 per 10, 000 for Asperger disorder respectively. Within international research, there is high variability within and between countries thus reducing the ability to detect statistical significance on the reported prevalence rate. This he attributed to the various sample size and the different definitions, identification and evaluative methods used within and across countries (Fombonne, 2005).

The debate on the prevalence of rates of autism continues to grow in North American and other post-industrial countries as it is unclear whether or not ASD rates have increased or if it is a matter of better diagnosis screening and knowledge leading to more identified ASD cases (Bryson & Smith, 1998; Fombonne, 2001; Kabot et al., 2003). Alternatively, a few studies suggest lower rates of ASD in developing countries in comparison to the global north. For example, in China, it is estimated that 1.1 per 1,000 children receive an ASD diagnosis (Saraceno & Saxena, 2002). Some factors that can affect the diagnostic process and global perspective on the rates of ASD include the social determinates of health shaped by social and economic conditions such as an increase in poverty, limited access to health care services and social exclusion to name a few.  For instance, an ineffective health care system in a developing country can create a barrier to accessing reliable health records on the distribution and causes of health-related issues about ASD; these records are very often inconsistent, incomplete or non-existent.

One such case is evident in Grenada; while the exact figure is not available, anecdotal reporting from the Autistic Foundation of Grenada Inc. a local Non-Profit organization, suggests that there are between 1000-2000 autistic individuals Grenada, which is about 1.83% of the total population. It is suspected that most individuals living on the island who may be autistic remain undiagnosed or misdiagnosed. Further, there are no formal policies or procedures within the health care or education system that encourage the documentation (data collection) of people living with ASD and other disabilities.

However, the Autistic Foundation of Grenada Inc. has been recently established, and part of their mission is to become a network leader in ASD and to explore the usefulness of epidemiological data to advise government and professionals towards improving diagnostic, education and support services. I argue that the act of counting "disabled" bodies and access to support and services it an important step towards inclusion and development but more importantly is the intentional consideration of the violence and exclusion they may have experienced (Children of Grenada, 2019).

It should be noted that data from the 2011 population and housing census reported that there was 26,016 cases of disability in Grenada with a total population of 103 328 persons (Census, 2011). These cases are representative of sight, speech, learning, and physical limitations. I assume that persons living with ASD diagnosed and/or undiagnosed are somehow reflected in those numbers. There is a need for improving and strengthening the detection, prevention, education, and training system in Grenada on disability and disability awareness for professionals, caregivers and community members to create a more inclusive and responsive space for people living with ASD and other disabilities.

Cultural and linguistic differences may also influence the global perspective on the rates of ASD. In South Korea, the stigma of autism is so pervasive that families will deliberately advocate for a different diagnosis to avoid shame and exclusion (South Korea, 2013). Furthermore, autism is diagnosed behaviourally often with the Autism Diagnostic Observation Schedule (ADOS), a tool referred to as the "gold standard" for observation and assessment of autism in the developed western countries.  ADOS is also used in developing nations for autism diagnosis; however, it does not account for the language differences and social interactions that are culturally based amongst the ethnic minority population. For example, in some Asian languages, there is no word to describe autism spectrum disorder (Dobson, Upadhyaya, Mcneil, Venkateswaran, & Gilderdale, 2001). In other cultures, the explanation for autism diagnosis is derived from more complex descriptive language rather than a single term

(Bernier, Mao, & Yen, 2010). These gaps can potentially contribute to undiagnosed or misdiagnosed individuals masking the prevalence rate in those communities.

Given the diversity of culture within and across various groups and the lack of consensus concerning diagnostic criteria, it would be a challenge to accurately assess prevalence rate across cultures and countries (Kim, 2012), However, attempting to conduct an epidemiological study with developing nations (non-Western countries) would be a valuable contribution to autism research and practice as there is a need to develop tools that are culturally sensitive and culturally appropriate for autistic individuals and their families.

### 2.2.2 Cultural perspective on autism etiology

This research is concerned with caregivers in Grenada perception of autism in supporting an autistic person or someone who may be autistic. It should be noted that across the literature that there are many unanswered questions about the cause of autism (Rapin & Dunn, 1995); it remains diverse, contentious and elusive (Bryson & Smith, 1998). I have already established that cultural background directly influences and determines how individuals, families and communities negotiate an ASD diagnosis and subsequent treatment decision (Ennis-Cole, Durodoye, & Harris, 2013).

What is well recognized within the literature is that ASD is on a spectrum and that those living with the disorder may exhibit a myriad of social, communication and behavioural presentations that can be challenging for their families and caregivers (Fombonne, 2001). The literature also suggests that the cause of autism is likely a combination of heredity (genetics), environmental and brain functioning (Geschwind, 2011; Karahmadi, Karimi, Kamali, & Mousavi, 2017; Ha, Sohn, Kim, Sim, & Cheon, 2015). However, the research on the etiology of ASD with diverse cultural groups [non-Caucasians] is notably lacking (Cucaro et al., 2007; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). As such, with regards to the cause of autism, there are several assertions and

disagreements amongst researchers, advocates, individuals on the spectrum, families, and communities. In what follows below are references from across ethnic and geographical lines to illustrate this point.

For instance, in the United States, African Americans generally associate an autism diagnosis to non-traditional factors such as dietary issues, food processing and contamination concerns (Ennis-Cole, Durodoye, & Harris, 2013; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Conversely, their Anglo counterparts typically associate the cause of autism to more traditional biological, neurological and environmental factors (Mercer, Creighton, Holden, & Lewis, 2006).

Genetic factors are recognised within the growing body of evidence-based research as a significant risk factor that can potentially contribute to an ASD etiology (Folstein & Rosen-Sheidley, 2001). Besides, some studies suggest that an intersection between susceptibility genes and environmental risk factors can contribute to autism pathogenesis (Herbert, 2010; Deth, Muratore, Benzecry, Power-Charnitsky, & Waly, 2008). This is true in particular for pregnant mothers who may be exposed to a set of prenatal risk factors such as teratogens, an agent or substance in the environment that can cause abnormal fetus development (Fembonne, 2005). Also in a control case study in China that investigated prenatal and perinatal risk factors to autism etiology, besides the eight other risk factors identified including second-hand smoking and maternal depression, the researchers reported that paternal age above 35 could be a potential risk factor (Zhang, et al., 2010).

A related study was conducted in Jamaica with 68 cases and in Aruba with 95 cases respectively on maternal and paternal age-related to the risk of an autism diagnosis. These studies both reported that there is an increased risk of ASD to a child born to older parents; fathers in particular (Rahbar, et al., 2012; Balkom, et al., 2012). It should be noted that in other studies, the relationship between advanced parental age as a risk factor for autism has also been rejected strongly (Glasson, et al., 2004; Tsuchiya, et al., 2005). Several other

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studies suggested additional environmental factors towards ASD etiology (Durkin, et al., 2008; Gardener, Spiegelman, & Buka, 2009; London & Etzel, 2000).

In a study by Gerber & Offit, (2009), a significant number of parents in the United States identified the vaccination for Measles, Mumps, and Rubella (MMR) as an environmental contributor to autism etiology. Further, studies by Norris, 2006; Landrigan, 2010; Matsuzaki, Iwata, Manabe, & Mori, (2012) compounded this argument as they reported that pregnant women in the first trimester who are exposed to common viruses such as cytomegalovirus (a disease that belongs to the herpesvirus group) and rubella are more prone to have a child living with autism experiencing comorbid disabilities such as gastrointestinal issues, neurological and cardiac impairments which contributes to an increase in morbidity rates.

Additionally, some parents based on anecdotal reports were concerned with the high level of mercury (neurotoxin thimerosal) in vaccination. They felt that this was causing autism and so as a precautionary measure, the Center for Disease Control and Prevention and the American Academy of Pediatrics requested that thimerosal, which is an addictive added in some vaccines to prevent germs from growing in them be removed from the medication (Ennis-Cole, Durodoye, & Harris, 2013).

 To date, there has been no evidence-based research to link autism with vaccines containing mercury-based compounds (Gerber & Offit, 2009). A recent study with 95,727 children receiving the series of MMR vaccines concluded that there was no increased risk to ASD (Jain et al., 2015). However, the notion that autism is connected to vaccination is still pervasive in the west reinforced by misrepresentation media (Draaisma, 2009). It would be interesting to find out if the caregivers in Grenada hold a similar understanding.

Correspondently, within the Jewish ultra-orthodox community in Israel, Shaked & Bilu, (2006) indicated that vaccination in addition to genetics, pre, and post-

natal difficulties is understood as the reason for the cause of autism. Shaked & Bulu, (2006) further highlighted that from a psychological perspective some within the Jewish community contend that parental neglect or bullying by other children within the community is responsible for autism; others within that community believe in a metaphysical account of the disorder, in other words living with autism or an autism diagnosis is understood to be divine and intentional by God. "Autistic children get to see the divine presence; their spirit sees it because they do not care about their bodies; they are all spirit" (Shaked & Bilu, 2006, p.14). Similarly, Mann (2013) in her dissertation on the autism experience in Jamaica reported on an autism etiology involving several aspects. First, mothers believed it was designed by God to have a child with ASD; second, it may be related to genetic risk, and third, it may be connected to the exposure to environmental toxins. I suspect given the proximity to Grenada (geographically and culturally) that the caregivers in this research may report similar etiology on autism.

Some of the disability studies in continental Africa associate the cause of disability including autism to witchcraft, evil spirits and curses (Ingstad & Whyte, 2005; Gona, Xiong, Muhit, Newton, & Hartley, 2009; Bello-Mojeed, Bakare, & Munir, 2014). For instance, on the Kenyan coast, 103 parents and professionals participated in a focus group study of the causes and treatment of ASD, in which they mentioned preternatural reasons for an autism etiology (Gona, et al., 2015). In another study with 134 healthcare workers in Nigeria, Bakare et al. (2009) stated that naturally (78), preternaturally (19) and supernaturally (36) of the respondents respectively reported on their perception of autism etiology. In the same study, one respondent had no opinion on the cause of autism.

Also, in a phenomenological inquiry in Zambia, Nyoni & Serpell (2012) highlighted the experiences of parents caring for a child on the ASD spectrum. They described that because the knowledge and awareness of ASD are lacking, members of that community are prone to link the cause of ASD to witchcraft and a deviation from Zambian cultural customs and traditional norms concerning marriage. The researchers also highlighted the resiliency of parents

within the Zambian community through humour, faith, and belief in the healing power of God necessary to cope with a diagnosis of ASD.

The conceptualization of Autism for some in the Latino Community is much more positive, with mothers believing that caring for a child with ASD is a "gift from God" that can be used to unpack the power, purpose, and sacrifice of God's love within their own lives and within the broader community and although they may not fully understand the disorder, some Latino mothers believe that acceptance will lead to a better quality of life for the person on the spectrum (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Salkas, Magaña, Marques, & Mirza, 2016). A slightly different account was reported in Zuckerman, et al., (2014), generally, having a child with a disability was seen as an embarrassment, and family burden and autism diagnosis, in particular, was associated with family dysfunction as the child's presentation was understood as "bad behavior," which can influence the parent's decision to seek assistance.

While it is essential to consider the cultural perspective on autism etiology, it should be interpreted with some restraint as the views on autism within and amongst cultural groups are not homogeneous but are as diverse as the genetic, biological and environmental etiology highlighted within and across the literature.

## 2.3 Cultural influence in diagnosis and treatment

I mentioned before that ADOS is generally accepted as the standardized tool for an autism assessment and diagnosis in North America and Europe and while it has been translated into 12 different languages across the globe, it still does not adequately and efficiently consider cultural nuances and language semantics in the diagnostic process (Harris, Barton, & Albert, 2013). As such, there is a gap in the literature as the research on exploring the diagnostic and treatment experiences with ethno-racial and non-western countries are limited. According to the literature, regardless of the etiology of autism, early

intervention, proper diagnosis, and evidence-based treatment are essential to increase the quality of life for those on the spectrum and their families (Rogers & Vismara, 2008; Elder, Kreider, Brasher, & Ansell, 2017). In what follows and as a linchpin to this discussion, I will engage with the question; how does culture affect the diagnosis and treatment of autism, and what are the impacts of families and caregivers?

### 2.3.1 Diagnosis of autism

Researchers in the United States have not been able to reveal any significant differences along racial lines (between Whites and Blacks) on the prevalence of autism (Yeargin-Allsopp, et al., 2003). However, across various cultural groups, they were able to identify age-related differences for an ASD diagnosis. Consider this study by Mandell, Listerud, Levy, & Pinto-Martin, (2002) who investigated racial differences and length of stay in treatment for an autism diagnosis of 406 children in Philadelphia who were also eligible for Medicaid. They reported that on average, white children receive a diagnosis at six years, African American children at eight years and Latino American children at nine years old respectively. The report also highlighted that African American children in comparison to the other racial groups required extended time in treatment before receiving the diagnosis.

In a follow-up study with the same sample, Mandell et al. (2009) stated that in comparison to white children, a formal diagnosis of attention deficit hyperactivity disorder (ADHD) was five times more likely for an African American and that they are nearly three times more likely for a conduct disorder diagnosis. The authors posit that the differences in the diagnostic procedure and outcomes amongst the various ethnic groups, including African and Latin American children, in particular, may be connected to the parents' understanding of the child's behavioural and emotional issues, which they may not attribute to a mental health concern, and so are less likely to disclose and seek medical and professional assistance.

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Another possible and vital account of the disparity amongst these racial groups may be connected to a lack of culturally sensitive and cultural competence amongst clinicians who may hold prejudicial and stereotypical expectations on the likelihood of ASD with non-white children (Ennis-Cole, Durodoye, & Harris, 2013. Other research suggests that clinicians within health institutions can be biased; for example, they judged clinical vignettes of European children as more autistic when compared to non-European children (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2008).  It would be necessary then for clinicians and other professionals to be more aware of cultural influences in the diagnostic process for people on the spectrum and their families.

In a study with 49 children (37 male and 12 female) in Saudi Arabia, Al-Salehi, Al-Hifthy, & Ghaziuddin, (2009) investigated the reason for referral and the clinical presentation or symptomology of the participants with an ASD diagnosis at a teaching hospital in that city. Al-Salehi et al. (2009) report the male to female ratio was 3 to 1; this ratio is consistent with recent research on the sex differences in autism spectrum disorders (Loomes, Hull, & Mandy, 2017). However, the researchers in Saudi Arabia reported that the females in the study were older than males at the time of referral. Further, they suggested that characteristic symptoms of autism may be detected later in Saudi females than in the males due in part to the cultural context of that region where females are less visible in public spaces; thus, families may not be pressured to seek treatment and support.

In a similar study Daley, (2004) conducted in-depth interviews and observations with 95 families in India, 80 male and 18 female (3 families had more than one child with autism) and reported that in comparison to North America and Europe, ASD symptoms are recognized at a later age. However, the author did not find any sex-related differences in the Indian context. The author postulates that the lateness in diagnosis may be attributed to limited professional expertise in ASD, and a different conceptualisation of developmental disabilities; for example, some professionals and parents in India's context do not consider

language delay in male to be symptomatic to autism as it is believed that boys will acquire speech later than girls (Daley, 2004).

In addition to prevalence and experiences across cultures and communities, this study is also concerned about the impact of an ASD diagnosis or the suspected presence of ASD can have on caregivers. A few studies reported on the initial and direct experiences of parents following an ASD diagnosis with entho racial families across counties. For instance, in a phenomenological study by Bilgin and Kucuk (2010) utilizing semi-structured interviews with 43 mothers in Turkey on their experiences of having a child diagnosed with autism, the mothers expressed a range of feelings from individual/ emotional experiences to social and collective experiences. In the individual/ emotional experience category, they reported feelings of grief 19%, emotional breakdown 12%, worry and hopelessness at 9%, respectively. One mother disclosed "I cannot ever accept the word disabled', people are asking me if I have a disabled child. I was upset" (Bilgin & Kucuk 2010, p.94-55). Another respondent commented "The only word is autism changes our lifestream. At first, I confined myself to my house because of my sadness. I was not talking to anyone; I was not wanting to see my loved people, as well. I always wanted to be alone, go to sleep. When I woke up, I wished this nightmare was finished." (Bilgin & Kucuk 2010 p.94). Under the social/collective experience and in addition to divorce and socio-economic stressors, mothers reported the lack of acceptance of an autistic child within Turkish society as extremely problematic and counterproductive to an inclusive society for people living with disabilities. One mother commented, "While I and my son are struggling with all difficulties in life, the biggest difficulty is insensitive people" (Bilgin & Kucul, 2010 p.96).

Similarly, in a study in Tehran, 43 parents were asked about their support needs caring for an individual on the autism spectrum (Samadi, McConkey & Kelly, 2012). When explicitly asked about their reaction to the diagnosis of autism, the parents' responses varied; 26 parents reported being shocked and depressed; 5 parents also disclosed being shocked; however, they rejected the ASD diagnosis; 9 parents reported uncertainty as they do not know what autism

meant; 2 parents from the study reported feeling relieved as they feared the child might have been diagnosed with a more complex developmental disability. Likewise, McCabe (2008), in a study in China, reported on the experiences of parents who have children with ASD. Utilizing the open-ended questionnaire, 78 parents provided context on their personal and families' experiences with a child on the spectrum; only 13 parents were available for a follow-up interview. In terms of how they responded to the child's diagnosis of Autism, 61 participants reported feeling shocked, upset and devastated about the diagnosis; 29 participants noted that they were unaware of the seriousness of the diagnosis and more specifically did not understand what the diagnosis meant; 10 participants disclosed being in denial about the diagnosis and 9 participants already suspected ASD; 6 participants reported assessing professional support while 2 parents disclosed parental conflict following the diagnosis. It is evident from these studies that caregivers experiences with supporting an autistic person varied, from experiences of intense and continuous grief and sorrow to experiences of clarity for others.

Krauss-Mars & Lachman, (1994), in a cross-cultural retrospective descriptive study in South Africa presented some thought-provoking information. The objective of the study was to explore the issues parents experience and their reactions when their child is diagnosed with a physical and mental health disability. Sixty-five parents were selected randomly from different ethnic groups within South Africa; 20 white parents, 33 mixed-race parents (coloured in South African Context) and 12 black or Xhosa parents. Xhosa refers to the second largest cultural group as well as a language in South Africa.

With regards to parents' reaction to the disclosure of an ASD diagnosis overall, most of the parents reported being satisfied with how the information was transferred, 80% whites, 78% coloured and 75% blacks. More specifically, parents reported on their reaction to the diagnosis: 48 % of the parents were able to describe the symptomology of the diagnosis, 23 % were able to identify their child's diagnosis, and another 25 % denied their child's diagnosis; 5 % of the parents were able to contextualize their child's diagnosis about the

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symptoms present; 2 % of the responses were vague. Parents' experiences and responses also varied based on race; for example, Xhosa speaking black parents reported that they did not receive an explanation of their child's diagnosis and were unable to ask clarifying questions. Similarly, when compared to the other racial groups, a few black parents reported being asked their understanding of their child's diagnosis. On the other hand, although most whites reported being asked for their understanding of the diagnosis, they were also more likely than any of the other groups to deny their child's diagnosis. Parents' experiences supporting an autistic person can be subjected to prejudice and systems of oppression which can negatively impact access to supports and services.

The diagnosis of a child with autism can have a multifaceted impact on families and caregivers. They can experience both positive experiences as well as challenges in supporting the individual. An understanding of the unique situation for families from ethno racial and less affluent non-western countries is essential to decipher the most feasible and responsive treatment and support needed for the person on the spectrum and the caregiver. The experiences of caregivers within the Grenadian context are unknown and it is hoped that this research will shed light on the challenges and benefits in providing care to those on or suspected on the autism spectrum.

### 2.3.2 Treatment for ASD

The literature is replete with reports on the differential treatment and access to healthcare services and supports for ethnic minorities in comparison to the dominant group (Ennis-Cole, Durodoye, & Harris, 2013; Newacheck, Hung, & Wright, 2002; Stevens & Shi, 2003). Some of the research has focused on autism specifically (Cuccaro et al, 2007). For example, African American children are diagnosed later than their white counterparts, and when compared to white parents, the concerns of an African American parent about his or her child living with a developmental disability is more likely to be discounted by physicians and other helping professionals (Mandell, Listerud, Levy, & Pinto-

Martin, 2002). In addition to health care, disparities in access and treatment for ethno racial minority groups, cultural mores also play a role in treatment decisions by families for autistic individuals; these treatment decisions are often connected to broader social, socioeconomic and geographical constraints to accessing support and services (Mandell & Novak, 2005). To be more precise, the relationship between caregivers and the professionals providing the intervention or treatment for an autistic individual is directly influenced by cultural factors within that particular society. Later in this thesis, this idea will become much more explicit concerning carers in Grenada.

In western Anglo cultures, there is much emphasis on individualism as opposed to a more collectivist orientation in minority cultures (Oyserman, Coon, & Kemmelmeier, 2002). For instance, in Canada and United States (individualist cultures), families supporting an autistic individual are more likely to rely on traditional and evidence-based interventions such as Applied Behavior Analysis (Simpson, 2005). Mostly, the goal of this intervention is that the autistic person will acquire communication, social, behavioural and adaptive skills, including food preparation and personal self-care to foster greater independence within "self." On the other hand, in collectivist societies such as Asia and the Caribbean, there is a greater emphasis on family and community (group); The sense of "self' of an autistic person is not understood to be individualistic and as such cannot be extricated from the communal identity. Hence, families supporting autistic persons from ethno racial and minority communities may reject the traditional treatments and interventions that are not interdependent, cooperative and compliant to the values within that family and community (Trembath, Balandin & Rossi, 2005); they are more likely to use non-traditional treatment and invention for disabilities including autism. The treatment and intervention can vary from culture to culture.

A review by Geest, (1997) on the role of traditional medicine (not to be mistaken with biomedicine) in the primary health services on continental Africa suggested that the health care system should not be expected to improve with the involvement of traditional healers significantly. However, from a community

perspective, access to traditional healers with expertise in healing rituals, and herbal treatment was essential for many families and communities. Further, Kromberg, et al., (2008) conducted a study with 722 children living with a disability and 100 traditional healers in the Bushbuckridge district in South Africa on perception, attitudes, and management of disability. The authors concluded that although effective treatment was available, many of the children living with disabilities were not receiving adequate treatment or education, which continues to hinder improvement and the best quality of life. They suggested, for example, that traditional healers in that region in an attempt to treat health conditions such as epilepsy with rituals and herbal remedies, these healers will often neglect to refer a child to a healthcare facility for more effective treatment. The social relationships amongst the carers and community members influence the understanding of disability and their treatment response. Necessarily, within these contexts, it would be important that health care professionals partner with traditional healers to access these communities and optimize the health outcome for those most vulnerable.

A cross-sectional study with 430 participants in Hong Kong concerning the use of Complementary and Alternative Medicine (CAM) in the treatment of ASD provides some insightful information (Lam, et al., 2009). Of the 430 participants, 98 were screened positive for ASD, of which 40 participants relied on CAM. The majority (17/40) reported choosing CAM on the advice of their family member; 13 participants disclosed choosing CAM on the advice of a medical professional; the other 13 participants chose CAM as they believed it would improve the quality of life for the ASD person. Some of the respondents had tried other interventions in the past as such 12 claimed in comparison the result would be better and another five reported that CAM would lower the toxicities of conventional medicine.  The most common CAM treatment was Acupuncture (47.5%), followed by Sensory Integration (42.5%) and Traditional Chinese Medicine (30%) (Lam, et al., 2009). They concluded that the data on the efficacy of cam in autism is still limited and that evidence based recommendations cannot be made without a larger randomized study.

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Another study assessed the applicability of the Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) program for 34 pre-school children in Hong Kong (Tsang, Shek, Lam, Tang, & Cheung, 2006). Moreover, the program was adapted and modified to fit within the Chinese cultural context. The 34 children were divided into a control group (16 participants) who received Individualized Education Plan (IEP), private therapy or group training but not TEAACH and an experiment group (18 participants) that received TEAACH curriculum components such as visual aid support. At a post-test follow up, the children that received the culturally adapted TEACCH program showed improvement in social, cognitive and adaptive capabilities. The researchers suggest that more study is needed within Chinese communities and home-based spaces to address any outstanding cultural hurdles further.

Another purpose of this study is to explore how caregivers become informed to support the person on the spectrum, and it is apparent from the literature that race and religion across cultural groups are relevant to attitudes in treatment and support decisions. According to Sue & Sue, (2008) African Americans are more likely to seek support for persons with disabilities from friends, family and the church. Asian Americans are also less likely to use professional support and services such as case manager and psychologist unless it becomes necessary in part to caregiver burnout, stress or intense aggression (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004) and Latino Americans may rely on spiritual healers or rituals as an intervention for various disabilities (Sue & Sue, 2016). Jegatheesan, Miller, & Fowler, (2010), in an ethnographic fieldwork study with three South Asian Muslim families living in the United States, investigated the families' perception of raising a child with autism within their cultural context. The parents reported that it was vital for them to raise their children following Islamic doctrine and planned to ensure that their children's experiences are typical and inclusive within the home and community settings. The parents' views of their children were in tension with autism professionals as these parents believed the opinions of the professionals were unhelpful to their children's overall development. Additionally, these parents reported being

privileged and strongly believed they were chosen by Allah (God) to raise "His special Child" and receive counsel from their Iman.

Similarly, Ultra-Orthodox Jewish families may seek advice from their Rabbi for health concerns (Pitten, 2008) and also may seek support from the medical community (Pitten, 2008; Shaked & Bilu, 2006). However, if there are conflicts and inconsistencies with the recommendations, families will default to the recommendations/ interventions provided by their Rabbi (Shaked & Bilu, 2006).

According to Ennis-Cole et al. (2013), "A families' socioeconomic status can make a tremendous difference in the intervention planning, education, technology utilization, and support services provided to a child with autism" (p.281). In addition to socioeconomic status, several studies suggest that geography plays a more critical role in determining the number of children diagnosed with ASD and access to specialty care (Mandell and Palmer, 2005; Palmer et al., 2005; Sturm et al., 2003). Inadequate resources and limited trained professions with autism expertise may contribute to a delayed diagnosis of autism as well as the lack of efficacy with interventions and treatment. Given the tremendous difficulty to access reliable diagnostic and appropriate treatment support for autistic people in the developing countries, Grenada in particular, it would be essential to highlight from across the literature, the adjustment experiences and support of ethno racial caregivers/ parents supporting an individual on the autism spectrum.

## 2.4 Caregiver adjustments and experiences

Another overarching question in the research is around caregivers learning to support the autistic person and what they believe is needed to improve on their experiences as carers and for the autistic person. Families' adjustments to caring for individuals with disabilities vary among and within cultural groups and are well documented in the literature, and for those caring for autistic individuals, their experiences can be even more debilitating (David & Carter, 2008). Providing care for an individual with complex needs across the lifespan

can be stressful for caregivers (Dyches, Smith, Korth, Roper, & Mandleco, 2012), notably, for mothers in cultures that place the burden to raise a child on the woman (Bello-Mojeed, Omigbodun, Ogun, Adewuya, & Adedokun, 2013). Within Grenadian culture, women are also mostly responsible for child-raising responsibilities. McCubbbin et al. (1998) define a stressor as "a demand placed on a family that produces, or has the potential of producing, changes in the family system" (p.6). This may include experiences of physical, psychological, emotional, social and financial stress from providing direct care to the autistic person and by extension an inadequate service system, social exclusion and social stigma that is associated with having a child with special needs (Green, 2007).

Concerning financial stress, findings from a study with 13 mothers of children with autism in Jamaica reported financial hardship and impact on their career advancement as many had to take breaks from their employment or had to quit their jobs to provide care to their child (Mann, 2013). Likewise, McCabe (2008), in his qualitative research reported that mothers would modify their work schedules, sometimes resigning from employment to meet the needs of their child. In addition to the financial stress, some of the literature reported on the social difficulties supporting a child with autism. These findings are corroborated by Cosser, (2005) and Emerson (2003), who suggest that families supporting a person with a disability are more likely to be economically disadvantaged in comparison to families without a child living with a disability. Indeed, the experience of disability as a financial burden is expansive.

As mentioned earlier, caregivers supporting autistic people are more likely to experience higher levels of mental, emotional and psychological caregiver burnout compared to caregivers supporting other disabilities (David & Carter, 2008). The high level of stress experiences of ASD caregivers may be connected to the complexity of the disorder. These include genetics, neurological issues, behaviour, sensory and communication issues. Mao (2012) states, "Parenting a child with autism involves additional stressors related to the child's challenges in communication, unpredictable and

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aggressive behaviours, social isolation, limitations in self-care, and lack of respite owing to an inability to find suitable substitute caregivers." (p. 864-865). In congruence with other studies, it is noted that caregivers supporting an autistic individual are likely to report symptoms of depression and anxiety (Estes, et al., 2013) and fatigue (Giallo, Wood, Jellett, & Porter, 2011). These health concerns can affect caregivers and their ability to provide care and support for the autistic person. It is essential to consider how caregivers respond to these stresses and their ability to cope as they continue to support the autistic individual.

### 2.4.1 Social Supports

According to the research, providing social support for families experiencing emotional, psychosocial and financial adversity can contribute to a reduction in their stress level and result in improvement in providing care and family coherence (Johnson, Frenn, Feetham, & Simpson, 2011; Pottie & Ingram, 2008; Mierau, 2008). These supports are available from formal and informal networks (Marshak, Seligman, & Prezant, 1999); formal supports refers to the involvement of professionals such as a case managers, speech and language therapist and occupational therapist to name a few, while informal support is family, friends and faith groups (Zablotsky, 2013).

For collectivist cultures and within developing nations, in particular, informal supports are critical since caring for an individual with a disability is understood in the context of the entire family unit, and the accessibility to trained professionals is limited. For example, Mann, (2013) in her research highlighted that for Jamaican mothers, social support from other mothers was beneficial in helping to reduce caregiver stress as they were able to access and share useful information on autism spectrum disorder. Correspondingly, Altiere (2006) in his report also noted that families established strong friendship networks with other parents of autistic children and that these partnerships have been a positive coping strategy in providing care to their child. The idea of a well-connected

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social supported system as a mechanism to address the challenges inherent to complex ASD presentation in supporting caregivers are evident in other studies, see (Ekas, Lickenbrock, & Whitman, 2010; Twoy, Connolly, & Novak, 2007; Gray, 2002).

Faith and/ or religion is another crucial coping mechanism for caregivers supporting someone living with autism (Shaked & Bilu, 2006; Nyoni & Serpell, 2012; Gray, 2002). For example, in a study with forty-five participants,' a sub-sample of 21 parents assessed the role religion plays as a coping strategy for families with children with autism. The report highlighted that positive religious coping was associated with a reduction in stress and better religious outcomes for parents; for example, parents may experience spiritual growth while caring for a child with special needs. On the contrary, parents who experienced negative religious coping presented with more significant depressive episodes and lower religious outcomes (Tarakeshwar & Pargament, 2001). Another study was done by Dardas & Ahmad, (2014) based on the stress level, coping strategies and quality of life for 184 parents of children with Autistic Disorder living in Jordan. Although Jordanian parents experienced significant high levels of psychosocial stress, they also reported adherence to faith/ spirituality as a helpful coping strategy to deal with dismal formal supports and educational programs available.

The literature provides sufficient evidence that social support, inclusive of religious provision, are essential coping approaches used by caregivers assisting persons on the autism spectrum. However, for many of these caregivers, access to informal support and particularly the formal support system can be incredibly difficult. The Caribbean region, which includes Grenada is no expectation.

## 2.5 Research Gap

Autism Spectrum Disorder (ASD) is a permanent complex neurodevelopmental condition that is understood to affect people regardless of race, ethnicity,

gender and socioeconomic level (Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001). Although the body of research literature related to Autism diagnosis, intervention and treatment is growing, the focus on individuals and their families from ethnic minority cultures and developing nations are still sparse, the Caribbean region included. With this perspective in mind, the purpose of this study is to address the dearth in the research by highlighting and expanding the knowledge base regarding the perceptions, knowledge and experiences of caregivers supporting autistic person in the Caribbean nation, Grenada.

I have searched through the literature and could not find a specific study that has had a dedicated focus on Autism Spectrum Disorder in Grenada.  I propose that for studies to be meaningful and beneficial they must be geographically and culturally contextualized and from the perspective of this research, it can internationalize and diversify the conversation about autism.

Although the perceptions, knowledge, and experiences of the participants in this study may not be homogeneous and reflective of the understanding and knowledge of all caregivers in Grenada or the Caribbean region for that matter, given the similarities across the region, the hope is that local and regional caregivers and persons living with and/ or suspected of ASD will be able to draw on the emerging commonalities and themes from this research. This research can contribute to the growing cross-cultural literature on the conceptualization of Autism and with particular attention to the local particularity in Grenada potentially there are implications for autism policy and practice on the island.

# Chapter 3: Methodology

## 3.1 Overview

In this chapter, I will outline the purpose of this study; I will then provide a brief description of the study location, Grenada in particular as it is necessary within the research framework used (Narrative reality). Following this, there is a discussion on the meaning of family/ caregiving to provide context to this study. I will define the philosophical underpinnings of my research, and I will explain the research design inclusive of the research recruitment procedure; I will then provide substantial context on participant narrative descriptions as it provides fruitful information for narrative analysis, and more importantly, it brings the participants and their experiences to life. The data collection section will then follow. Details on the data analysis process will be offered as well as perspective on the role of reflexivity and its contributions throughout the research process, and finally, I will speak to the ethical consideration applied in the study as a safety measure for the participants throughout the research process.

## 3.2 Purpose of the study

The purpose of this research was to explore the experiences, perceptions, and understanding of caregivers (parents, relatives, and friends) in Grenada who support autistic individuals or persons that maybe autistic.The questions that guided this study include:

1. What are the lived experiences of caregivers supporting Autistic individuals and/or persons that may be Autistic in Grenada?

2. How do caregivers supporting Autistic individuals and/or persons that may be Autistic conceptualize these experiences?

3. How do caregivers learn to become well-informed to support Autistic individuals and/or persons that may be Autistic in Grenada?

4. What further support do caregivers identify they need?

5. What recommendations would caregivers supporting Autistic individuals and/or persons that may be Autistic suggest is needed to improve the quality of life for themselves and the autistic person?

## 3.3 Location of the study

Nestled between the Caribbean Sea and the Atlantic Ocean is the English-speaking island nation of Grenada, with an estimated population of 109 000 people primarily of African descent and a land area of approximately 344 square kilometers (The World Factbook). The country is a Tri-Island nation, including Carriacou and Petit Martinique and several other small uninhabited islands. The main island (Grenada) is separated into six different parishes: St. George, St. David, St. Mark, St. John, St. Andrew and St. Patrick.

This research was conducted on the main island (see figure 1).



http://www.emapsworld.com/grenada-parishes-map.html

**Figure 1: Shows the Tri-Island state of Grenada, Carriacou and Petit Martinique, including the divided parishes on the mainland.**

Grenada is volcanic in origin with an incredible mountainous landscape, lush vegetation, and remarkable seashore line. A former French and then a British colony, the island retained influences from its colonizers in various sectors, including architecture, culture, governance and the education system to name a few (Crask, 2009). Grenada became an independent country in 1974, and within the British, Commonwealth is currently a constitutional monarchy, with a Prime Minister and Queen Elizabeth II as Head of State, represented by an appointed Governor-General (Common Wealth, 2020).

The Ministry of Social Development, Housing, and Community Empowerment is responsible for the social inclusion and social development of citizens on the Tri-Island state. In particular, the Ministry is determined to address issues around poverty, child abuse, mental health, disability, addressing individual and family conflicts and other socio-political and socio-economic concerns through the development of policies and implementation of social supports program and services geared towards improving the quality of life for all Grenadines including families and individuals living with disabilities (Ministry of Social Development, 2018).

Concerning autism, I was unable to find documented specific policies, support, and services within the various government ministries. This is part of the problem the caregiver faces, limited resources and no clear policy or procedure to address the needs of the autistic person and their family. Furthermore, it is unclear how many people in Grenada are autistic or may be autistic. There is no national registry, but what is certain is that there is a significant lack of meaningful programs and services for caregivers and people on the spectrum.

## 3.4 The context of the study

Family life within the Caribbean region exists within a milieu of political, social, cultural, religious and ethnic differences, which can influence family structures (Barrow, 1999). For instance, African-Caribbean family life and childrearing

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patterns have been uniquely shaped, primarily, by the experiences of slavery, colonialism and socioeconomic context (Sharpe, 1996). These realities have resulted in a family structure that is often matricentric and includes nurturing patterns that embrace absent fathers (due in part to wage male migration); households led by grandmothers, common-law unions and child- shifting practices, where a child is sent to live with relatives for varied reasons (Sharpe, 1996). Given the apparent complexity of family structure within the Caribbean region, Grenada included, the term "family" is often overextended to include both formal and informal unions and relationships within and across different households (Barrow, 1999). In essence, within Grenadian culture, it takes a community to raise and care for a child. For this study, a caregiver is related to anyone (parent, relatives and friends) within the Grenadian cultural context who are providing primary care or who is most responsible for the autistic person or persons that may be Autistic.

There has been an increased consideration of the outcome for families/ caregivers supporting autistic persons. The literature suggests that given the complexity and the multidimensional care needs of an autistic individual, some caregivers have reported a high level of stress, depression, anxiety, psychological trauma, physical abuse and other mental and physical health concerns (Hoefman, et al., 2014). Furthermore, caregivers reported financial hardship due to the high out of pocket cost to access day program placement and respite support workers; also, they narrated loss of employment or underemployment given the responsibility and commitment to care for a person on the autism spectrum (Bromley, Hare, Davison, & Emerson, 2004; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007 & Kuhlthau, Hill, Yucel, & Perrin, 2005).

Caring for an autistic individual, lower functioning, in particular, can be a stressful and challenging experience for families and caregivers and potentially can negatively affect the family functions (Johnson, Frenn, Freetham, & Simpson, 2011). For example, a parent who is experiencing a plethora of psychosocial problems may be challenged in their ability to efficiently support and implement a behavioural support plan for the autistic person. As mentioned

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in the previous chapter, the research states that intervention and supports for autistic persons often require parent and caregiver involvement (Mcconachie & Diggle, 2007). Therefore, I felt it would make sense to explore within the context of Grenada, caregivers' involvement and experiences providing direct care and support for autistic individuals or persons that may be autistic. Additionally, I felt it would be useful to document these caregivers' knowledge, skills and practices providing support to the person on the spectrum. I felt that it was essential to get a first-hand and indigenous account about autism from these Grenadian families/ caregivers to inform or at minimum begin the conversation around assessment, education and support strategies, that are appropriate and culturally responsive, designed to improve the quality of life for both caregiver and the autistic person

Furthermore, Grenada is considered a low-income country and lacks the economic and human capital needed to provide specialist supports and services. The most accessible and reliable way to assist individuals living with various challenges, including those on the autism spectrum would be through supporting, educating and advising their caregivers. Improved awareness by these caregivers on the success and challenges may be the precondition necessary to foster advancement towards more appropriate support, awareness of the lived realities of those living with disabilities. Further, these caregivers and those living with disabilities will be better prepared to advocate for social, economic and political justice for this marginalized group.

## 3.5 Methodological Foundation

Ontology is the study of 'being' and is concerned with the structure of reality and all that is or exists (Crotty, 1998). According to Snape and Spencer (2003), ontology is defined as the nature of the world and what we can know about it. Furthermore, Ormston et al. (2014) posit that ontology is concerned with "whether or not there is a social reality that exists independently from human conceptions and interpretations and, closely related to this, whether there is shared social reality or only multiple, context-specific ones" (p.4). Sequentially,

epistemology is concerned with how we engage with the world and make sense of it; in other words, it deals with our understanding of the nature of acquiring knowledge (Richards, 2003). Cohen, Manion, and Morrison (2007) state that epistemology is about the assumptions we make about "the very bases of knowledge- its nature and form, how it can be acquired and how it is communicated to other human beings" (p.7).

Primarily, epistemology seeks to answers the question "how do we know?" and engage with various concepts including our senses, logic, reasoning, memories, ideas, thoughts and emotions, and how we relate these concepts to reality and whether those understandings are legitimate or not. Therefore, the ontological and epistemological assumptions we hold about knowledge influence how we engage with and unpack social behaviours and lived realities. For example, if a researcher holds the position that knowledge is objective or that truth is static, and that reality can only exist independently of our beliefs or understanding, that researcher will then, necessarily, rely on data collection and data analysis methods that are deemed more objective, value-free, generalizable and replicable (Wellington, 2000). On the contrary, if a researcher's conceptualization of knowledge is understood to be subjective, it will demand of the researcher more involvement with subjects and allegiance to methods that will explore and understand the researcher's perception and interpretation of the world and social reality of the people being studied.

To this end, the ontological and epistemological positions which underpin this study are grounded in constructionism and Interpretivist philosophical positions (Soini, Kronqvist, & Huber, 2011). Generally, these philosophical assumptions form the bases of my understanding of social research and my thinking and understanding of realism in this world. For this reason, these assumptions informed the research design and data collection methods adopted in this study. As a researcher, what I understand as reality is subjective and will vary from person to person. Hence there are as many realities as there are people (Guba & Lincoln, 1994). According to Carson et al. (2001), this philosophical position provides a structure that is personal and flexible,

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characteristics that are necessary to make sense of meaning in human interactions, and as Crotty, (1998) claims "knowledge and meaningful reality are constructed in and out of interaction between humans and their world and are developed and transmitted in a social context" (p.42).

Similarly, Ormston et al. (2014) assert, "all meanings are a product of time and place. The researcher cannot capture the social world of another or give an authoritative account of their findings because there are no fixed meanings to be captured" (p15-16). That is to say; people construct meaning in diverse ways even when they are faced with the same situation or circumstance; each person will bring their perspective and views to the forefront. Additionally, these perspectives (individual and collective) are not fixed but are always changing based on the milieu.

As it relates to this research, the goal was to elicit a subjective understanding and interpretation of the participant's experiences and conceptualization supporting autistic individuals or persons that may be autistic within the Grenadian cultural context. Primarily, the study sought to bring to consciousness the hidden experiences (untold stories) within the historical and sociocultural complexity of disability discourse in Grenada, rather than to prove a hypothesis, draw a definitive conclusion or provide objective generalization on disability, autism in particular. In this regard, I thought it would be appropriate for my research to follow qualitative approaches. Denzin & Lincoln (1994), provide a comprehensive definition:

> **Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena regarding the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts—that**

**describe routine and problematic moments and meaning in individuals' lives. (p. 2).**

The core principles of a qualitative research paradigm align well with two critical values of this study design. Firstly, the study was exploratory, a design considered when there is limited or no previous studies/knowledge on an issue (Schwab, 2004; Brown, 2006). Consequently, this exploratory qualitative research was intended to provide more in-depth understanding or insight on the attitude, opinions, behaviours and the lived experience of caregivers supporting persons living with/suspected of ASD or as Schwab (2004) asserts "findings from exploratory research are better thought of as hypothesis-generating" (p.294).

Secondly, I was committed to ensuring that this study was grounded in the understanding and interrogation of how these Grenadian caregivers experience supporting persons with autism on their terms and within that specific cultural context. To this end, I relied on an emergent method in narratives, an approach Gubrium & Holstein (2009) call narrative ethnography or narrative reality. This approach seems most appropriate to examine the caregiver experience and their meanings within the Grenadian cultural context as it allowed me to carefully investigate the participant's experiences by drawing on my ethnographic observations of our interactions and story sharing in the spaces/environments where narratives are produced. I will provide a brief account of narrative ethnography before detailing other aspects (recruitment procedures, participants' information, etc.) in the research design.

### 3.6 Research Design

This study was developed within the framework of narrative ethnography, which is predominantly used in the fields of anthropology and sociology. The narrative ethnography approach is underpinned by traditional ethnographic data generation methods (observation, interviews, document analysis) enabling the production of spoken, written and narrative data (Gubrium & Holstein, 2009).

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I chose narrative ethnography as the methodological framing for the dissertation as previous to the start of this research and before migrating to Canada, I had spent most of my child and adult life in Grenada and am still very actively engaged within the community both in the diaspora and locally. It should be emphasized that Grenadian society follows oral tradition. In this regard, I felt narrative, or storytelling can help accomplish all kinds of effort. First, the narrative approach can be valuable as it gives a first-person account of a place (Grenada) and people's (caregivers) experiences as it is typically embedded in organizational or social settings. Second, stories can report on what events took place, can help explain the situation and suggest what should be done next, and third within the narrative approach there is an understanding that storytelling is not exclusively that of the tellers but that the story's audience is essential in the interpretation, resisting, construction or (re)- telling of the story (Gubrium & Holstein, 2009). For this study, I incorporated narrative interviews supported by observational data generated from these interviews over a relatively short period (four weeks) specific to the research design, and questions see (Figure. 2). I will expand on this later in the chapter.
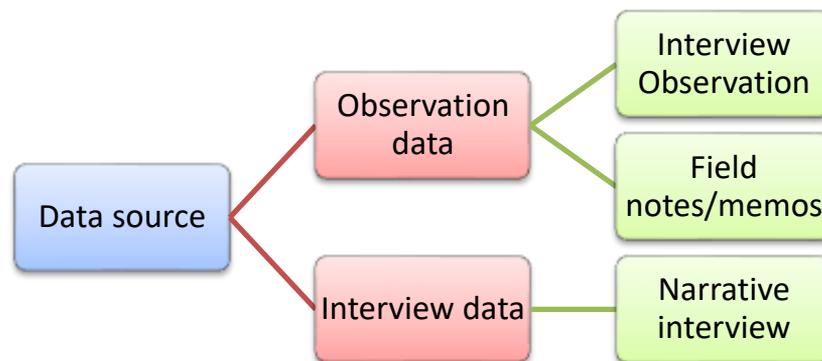


**Figure 2. Summary of data generated during the study over 4 weeks period**

### 3.6.1 Narrative Reality

In conventional research, much of the emphasis on narrative analysis centers on written text (Sandelowski, 1991). Gubrium & Holstein, (2009) suggest that traditional narrative analysis seems to focus exclusively on the stories that are told and then disseminated and that they are restricted to what is produced by

the text and does not consider the social organization and interactional dynamics of storytelling. Instead, Narrative reality offers an alternate form of analysis that reflects "communicative mechanism, circumstances, purpose, strategies, and resources that shape narrative production" (Gubrium & Holstein, 2009 p. viii). In other words, the context and environment in which stories are told and retold (the reality) is as important as text that is produced and encourages researches "to analyze stories and storytelling in an extended framework, to document what the communication process and its circumstances designated as meaningful and important, together with the various purposed stories serve" (Gubrium & Holstein, 2009 p.2). Of particular interest in this study is how caregivers in Grenada told their stories on supporting an autistic person or someone that may be autistic and how these stories or "social realities are produced, organized, understood, and shared by individuals and societies" (Mura & Sharif, 2016 p.196).

The analysis of Narrative reality encourages us to consider several circumstances in the production and transmission of stories; these include an understanding and appreciation for fieldwork (narrative work & narrative environments) where stories are produced, it also considers the importance of analytical bracketing or moving intermittently between narrative work and narrative environments to understand narrative reality, a point I will come back to later. Gubrium & Holstein (2009) also suggest an analysis of interactional terrain, in other words, the reason or people that prompt storytelling and more importantly, how people produce narratives or storytelling that makes sense for them and others. Narrative ethnographic researchers are also asked to consider an analysis of situational terrain, which is the physical and socio-cultural situation in which narrative work unfolds, an acknowledgment that environment/ material can impact how stories are told and understood.

This Narrative reality approach fitted well within the objectives and boundaries of my research as well as within the ontological and epistemological position outlined above.

## 3.7 Recruitment and Procedure

Following ethics approval from Lancaster University, the study went through five phases; this includes, three distinct recruitment phases, a data collection and analysis phase and finally a feedback phase. For a Schematic representation of the recruitment, data collection, and analysis process (see Figure 3 Appendix G). First, due to the specificity of the participant's invitation criteria and to achieve a maximum variation sample, purposive sampling was used to recruit participants for the research under discussion (Creswell, 2009). The study inclusion criteria were: (1) English Speaking and living in Grenada, and (2) a caregiver of an autistic person or person that may be autistic. oIf these two criteria were met, there were no exclusion criteria.

An initial sample size of 10 participants was invited to the study. This small sample size was considered as I was uncertain about access to a larger sample given the novelty of autism education and awareness within the research and practice context in Grenada. Moreover, supported by Dukes (1994); Crouch & Mckenzie (2006) this small sample size I felt may have been sufficient to allow for the identification of emerging concepts and consistent patterns to the point of redundancy or data saturation. Also, it is noted that a small sample size can be advantageous in exploratory research as it allows for an in-depth and comprehensive interview process and analysis (Crouch & McKenzie, 2006). The final sample included interviews with 15 caregivers.

Initial participants were recruited with assistance from the Autism Foundation of Grenada and through key informants from the Ministry of Education Special Education Department. An invitation to participate was first sent via email asking the coordinators from these organizations to share the research flyer (see Appendix B) and the participant information sheet (see Appendix C) with potential participants they believe would be able to provide sufficient information on their experience caring for a person living with or suspected of autism. Four caregivers expressed an interest and subsequently took part in an interview and participant observation.

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In an attempt to reach more potential participants, a "snowballing" method was also used. According to Creswell, (2007), snowball sampling is a technique where a research participant or community member gives the researcher the name of other potential participants, who, in turn, provides the name of other participants, and so on. Furthermore, this method can potentially provide the researcher with in-depth and useful information on the social relationships, social dynamics, social networks and community organizing of the research participants (Noy, 2008). Through this method, a further six participants agreed to take part in the study. These participants were also provided with a copy of the research flyer and participant information sheet for review.

To achieve maximum variation in the sample and to access additional participants, I posted the research flyer to an online local newspaper on the island.http://www.nowgrenada.com/2018/03/study-on-primary-caregivers-of-persons-living-with-or-suspected-of-autism-spectrum-disorder/ (See Appendix D), as well as to other social media sites such as Facebook, Twitter, and LinkedIn. Five additional caregivers agreed to take part in the study and coincidentally; these five participants were representative of caregivers from the different parishes on the island living in both urban and rural areas. The pervious participants were mainly from three parishes. Although not a requirement in this qualitative research, I was pleased that there was at minimum one participant from each parish to add to the rich and diverse narrative of these caregivers' practices and experiences across the island.

I then followed up individually with the 15 potential participants via telephone to provide additional information about the research as well as to provide clarification and to address or answer any concerns they had. At that time, I also confirmed that the potential participants met the research inclusion criteria in particular that they were residents of Grenada who spoke English and were most responsible for an autistic person or someone that may be autistic. For the caregivers that were supporting a person without a formal diagnosis of autism, I followed up with a series of questions to assess their eligibility for the research. These included inquires around the individual developmental history and cognitive milestones and on their communication skills (verbal and non-

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verbal). I also inquired about their relationship to others and the world around them including behavioral presentations. Most of the individuals that may be autistic were already connected to the Autistic Foundation of Grenada which gave the reassurance that they met the inclusion criteria.

A tentative date to meet for the interview/observation was also agreed to on this initial contact. This was important as my time on the island was limited (4 weeks), and I wanted to ensure that all 15 caregivers would have the opportunity to share their stories without being inconvenienced. Once I got to Grenada, I followed up with the participants again reviewing the purpose of the study, explaining that their involvement was voluntary, explaining the data collection procedures as well as the risk and potential benefits from taking part in the study. The informed consent form (See Appendix E) was shared electronically where possible (a few participants did not have access to email and the internet), and at that time, the participants were asked about their preference for the interview/observation location and agreed time to meet was set up.

In addition to the reviews of the participant information sheet and informed consent from the earlier phases of the recruitment process, this procedure was repeated with the participants immediately before conducting the interviews; they were allowed to ask any further clarification questions or raise their concerns. Also, I used the opportunity to remind them that the interview was voluntary, will be audio-recorded and will be transcribed verbatim. The participants were also reminded that their names will not be used in the analysis or the final report. Once I was satisfied that the participants understood and had no additional questions or concerns, I asked them to provide their signature indicating their consent on the form. No participant objected to this request.

As I mentioned above the final stage in the recruitment and procedure process was the feedback phase. I returned to Grenada after the collected data was finally analyzed to report on the key findings and for further feedback and validation from the participants and additional changes where it was necessary based on the participant's feedback. A primary focus of the follow-up meeting was to ensure anonymity and respectful representation of the caregiver's

stories in this thesis. I wanted to be sure that the participants all felt comfortable with what was represented, given the collective culture and close-knit communities on the island. No participant protested the final analysis.

## 3.8 Participants

Of the caregiver participants, 11 were female, and four were male, and all were from separate families. The caregiver's age ranged from 20 to 70 years old. Their relationship to the person suspected or on the autism spectrum varied, comprising of parents, grandparents, relatives, and friends. Two caregivers each had two individuals living with or suspected of ASD.

Between them, the caregivers were supporting 17 people living with or suspected of autism, of whom four were female, and thirteen were male, which may be a representation of the male to the female gender distribution of those living with ASD within the broader autism community and research literature, see (Werling & Geschwind, 2013). Only 5 of the 17 individuals were officially diagnosed with ASD.

The characteristics of the participants are provided in Table 1. Participants appears in the order the interview was conducted, followed by a more detailed narrative description to provide some facts on the participants themselves. These narrative descriptions are practically important in this narrative research as they represent each participant's diverse reality; as a mother, father, grandparent, relative, friend, and notably as part of a unit supporting autistic individuals or those that may be autistic. These descriptors explore each caregiver's reality and bring the experience as carers to life within the Grenadian cultural milieu. Also, personal accounts are often captivating and emotionally moving which gives artfulness and texture to people's lives

| PARTICIPANT pseudonym | GENDER | AGE-RANGE | PARISH | RELATIONSHIP TO INDIVIDUAL SUPPORTED | DEPENDANT pseudonym | AGE OF INDIVIDUAL SUPPORTED | GENDER OF INDIVIDUAL SUPPORTED | AUTISM DIGNOSED OR MAY BE AUTISTIC |
|---|---|---|---|---|---|---|---|---|
| **Nia** | Female | 25-30 | St. George | Mother | Lynn | 8 | Female | May be Autistic |
| **Ayanna** | Female | 25-30 | St. Andrew | Mother | Ryan | 8 | Male | May be Autistic |
| | | | | | Rheeda | 11 | Female | May be Autistic |
| **Dante** | Male | 50-55 | St. George | Father | Marc | 19 | Male | Diagnosed |
| | | | | | Mikey | 21 | Male | Diagnosed |
| **Candyce** | Female | 45-50 | St. George | Nephew | Lyndon | 13 | Male | May be Autistic |
| **Aaliyah** | Female | 45-50 | St. Andrew | Mother | Robert | 15 | Male | May be Autistic |
| **Suzette** | Female | 65-70 | St. Patrick | Grand Mother | Rolsten | 10 | Male | May be Autistic |
| **Nerissa** | Female | 30-35 | St. Patrick | Mother | Angelo | 14 | Male | May be Autistic |
| **Delphine** | Female | 25-30 | St. Patrick | Mother | Billy | 7 | Male | Diagnosed |
| **Charlene** | Female | 20-25 | St. John | Family Friend | Lookie | 8 | Female | May be Autistic |
| **Lathan** | Male | 40-45 | St. Andrew | Father | Hannah | 9 | Female | Diagnosed |
| **Khadija** | Female | 35-40 | St. Mark | Relative (Cousin) | Peter | 15 | Male | May be Autistic |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Dorsey** | Male | 40-45 | St. George | Father | Dillon | 13 | Male | May be Autistic |
| **Malik** | Male | 35-40 | St. George | Father | Shane | 8 | Male | May be Autistic |
| **Samara** | Female | 65-70 | St. Mark | Grand Mother | Walter | 14 | Male | May be Autistic |
| **Cynthia** | Female | 55-60 | St. David | Mother | Kevin | 33 | Male | Diagnosed |

**Table 1: *Participant's Characteristics with supplementing information on the autistic individuals***

### 3.8.1 Narrative Description of Participants

**Nia-** Is a parent of an 8-year girl suspected of living with ASD. I met Nia in the south of the island, and she was one of the first people who showed interest in the research. We met at a restaurant, and although it was a loud environment with some distraction, it was where Nia felt most comfortable being interviewed. Nia and I discussed in great detail some of the challenges and successes of caring for her daughter, and at times Nia was visibly emotional and animated with her expression.  She expressed gratitude for the opportunity to share her experience.  Nia's daughter attends a special education program in the south of the island.

**Ayanna**- At the time of the interview was in her mid-twenties and a single parent to an 8-year-old boy and an 11-year-old girl both suspected of living with Autism. They are both attending primary school within the regular education school system. I met Ayanna in Saint Andrew's, the largest parish in Grenada. An interview was conducted at a neighbour's residence as Ayanna was uncomfortable hosting in her own home. She disclosed being unemployed and spoke about the difficulties of caring for her children whom she loved dearly. She was eager to share her story and is hopeful that things would, in her words "get better for her and her children."

**Dante**- At the time of the interview, Dante was a husband and father to two adult sons diagnosed with autism. One of his sons recently graduated from secondary school; the other attended a special education program. Dante was introduced to the researcher by a friend who was working within a government ministry on the island. Dante was very willing and excited to share his experience supporting his children. As a working professional who is also involved in research, he highlighted the importance of sharing stories and collecting anecdotal evidence as a strategy towards raising awareness on various social and political issues. The interview with Dante was conducted in Dante's workplace office. The setting was quiet and relaxed and provided the opportunity for a lengthy interview.

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**Candyce**- was a married woman in her mid-fifties living in the south of the island at the time of the interview. Along with her husband, she was caring for a nephew suspected of ASD; he attends a special education program. At first, Candyce was suspicious about the purpose of the research and was also hesitant about being audio recorded. However, after reviewing the research and providing clarification on the recorded audio; she agreed to continue in the research project. The interview with Candyce occurred in her place of employment, and although relatively short it was very insightful.

**Aaliyah**- When I met Aaliyah, she was in her mid-forties and was unemployed. She was caring for her 15-year-old son suspected of ASD. I met with Aaliyah in her home in the northern part of the island. She was not willing to share on the educational opportunity for her son. The interview was difficult for Aaliyah, and at one point she requested that the interview stop as she became very emotional. She was frustrated that she was sometimes unable to provide for her son and seemed disgruntled with the lack of involvement of other family members. Despite these challenges, Aaliyah was willing to continue the interview.

**Suzette-** When Suzette and I met, she was in her late sixties and was the grandparent to a ten-year-old boy suspected of having ASD. He attends a primary school within his parish. She explained that the boy's parents migrated to North America 4 years ago, leaving the day to day responsibility to care for her. She noted that the boy's parents (her daughter and her partner) are still very much involved in providing financial support. The interview with Suzette occurred on the northern tip of the island within her home. It was a welcoming, quiet and relaxing environment, and the ten-year-old boy was also present and at times engaged with his grandmother throughout the interview. When Suzette was not speaking, she would gaze towards the boy with a radiant smile. It was clear to me that they had an incredible bond. Suzette thanked the researcher for the opportunity.

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**Nerissa**- Nerrisa and I also met on the northern tip of the island; the interview was conducted in a community centre overlooking the parish's spectacular coastline. When we met, she was in her mid-thirties and caring for her 14-year-old son together with her partner. Her son is a student in a special education program. Nerissa was not very talkative; however, concretely shared her story as a caregiver. She also spoke in great detail on her hopes and fear for her son and made suggestions on how things can be improved.

**Delphine**- At the time of the interview, Delphine was in her mid-twenties, married and the mother of a seven-year-old boy diagnosed with ASD. Her son attends primary school with additional class supports provided by the family. The family lived in a beautiful community in the parish of St Patrick's. Delphine was one of the first people to respond to the research flyer and was eager to share her story. She noted a desire to learn more about ASD, and although raising a special needs child can be difficult, Delphine spoke about the privilege of finding support in her partner and family in raising her son.

**Charlene-** Was a sole caregiver from the parish of St John. She heard about the research via social media and was very interested in sharing her experience of caring for an eight-year-old girl in her community. Charlene disclosed that after the girl's biological mother became permanently disabled, she took it upon herself to be the most responsible person for the girl's care and wellbeing. The young girl is a student at a program for children living with various disabilities. At the time of the interview, Charlene was in her early twenties and single, she had no children of her own and shared residence with her family. Charlene and I met in a small but cozy room in her parents' house; periodically, her father would come in and contribute to the interview. Although it was distracting, it provided useful information and was evident in the bond within that family unit about caring for the 8-year-old girl.

**Lathan-** was introduced to this writer by another participant who early expressed interest in the research. He was hesitant about meeting me and had a few questions about my research intention and more specifically, how his

participation will benefit his nine-year-old daughter. I reiterated the research objective and redirected him to the participant information sheet. Eventually, Lathan agreed to participate and shared rich and profound experiences caring for his daughter. His daughter has an official diagnosis of ASD and is a student within the regular primary school system. At the time of the interview, Lathan was in his early forties, employed and lived in the parish of St Andrew. He was raising his daughter with his wife. We met in the parsonage of the church to which he is affiliated.

**Khadija**- Followed up with me after receiving the flyer for the study via social media. She was unsure about her eligibility and had a few clarifying questions. When the interview was conducted, Khadija was living in the parish of St. Mark on the west coast of Grenada. She was in her mid to late thirties, married and employed. She talked extensively about her 15-year-old cousin, who is suspected of living with autism; she disclosed that for the past ten years, she has been helping out with parenting/ caring for the 15-year-old child as it has been incredibly difficult emotionally and financially for the child's single mother. Her cousin attends a special education program in the north of the island. Khadija and I met in the backyard garden at her residence, the environment provided an opportunity for open conversation, and Khadija was very motivated to share her narrative in hopes that it would help other families on the island.

**Dorsey**- When I met Dorsey, he was in his mid-forties, a single parent, caring for a thirteen-year-old boy living with or suspected of ASD. He lived in the parish of St George. Dorsey was introduced to me by his son's teacher; his son attends a special education program. We spoke a few times on the telephone but had difficulty arranging a time to meet, given his hectic work schedule. Eventually, we would find time to meet to explore his experience as a caregiver of someone on the spectrum. I met Dorsey on a quiet Sunday evening at his home, his son was present throughout the interview, and although he disclosed it was difficult for him to share his story as a single parent caring for a total of 4 children, he felt that sharing, in the long run, will help his son.

**Malik**-Before I met Malik, I was informed about him by one of my professional connections on the island and was told about how eager he was to participate in the interview. However, when we met, he seemed disinterested in the research. It turned out that Malik was misinformed or misunderstood the purpose of the interview. He thought that I was going to meet with his son to assess and diagnose his ASD. I explained the purpose of the study and the potential benefit to him and his son, and after some hesitation, he agreed to participate and shared willingly on his experience caring for his 8-year-old son. At the time of the interview, he was in his early thirties, living in the parish of St George. He was raising this child with his partner.  His son attends a private school on the island. Accompanied by his son, Malik, and I held our conversation in a private room at a local NGO in the city.

**Samara**- is a grandmother in her late sixties caring for a 14-year-old boy suspected of ASD. She is raising the boy together with her older grandson. The family lives in the parish of St. Mark and I had the privilege to interview in office space within the family home. It was small, cozy and comfortable to conduct an interview. Samara spoke about the challenge of raising her 14-year-old grandson and disclosed that in addition to his suspected ASD, that he has other medical complications. He attends a specialized program for people with disabilities. Samara spoke extensively about how her grandson came into her care and was enthusiastic about the opportunity to share her experience with me. Samara found out about the research from another participant.

**Cynthia**- At the time of the interview, Cynthia was a married woman in her mid-fifties, providing care to her severely autistic adult son. He currently does not attend any day program. Cynthia disclosed that she had lived in North America for an extended period, where her son received the diagnosis and extensive assessment and intervention for the disorder. The interview was difficult for Cynthia who requested several breaks from the interview but was determined to share her full narrative. Cynthia and I met in the comfort of her family home in the parish of St. David in the south-eastern part of the island.

## 3.9 Data Collection

Narrative ethnography pays close attention to the intersection between the narrative itself and observation of the context in which it is produced (Gubrium & Holstein, 1999), and allow the opportunity to combine story sharing as a pedagogical practice with attention to the interactional and material context of narrative production. Methodologically, I combined a range of research activities to generate ethnographical and narrative data. First, I formulated a semi-structured interview schedule, which served as the foundation for my research. Second, I observed the interactions with the research participants while engaged in the storytelling process. Finally, I recorded field notes to include the observations from the interview as well as my reflection of the interaction with the participants. In line with narrative ethnography, my research process was reflexive, constructivist and developed as an "ethnographic dialogue to create a world of shared intersubjectivity" (Tedlock, 1991, p.70) in this case amongst caregivers supporting an individual living with or suspected of autism in Grenada (see the next section).

### 3.9.1 Semi-structured interview

I formulated a semi-structured interview schedule as the principal and most suitable data collection tool for this research (See Appendix D), as I felt it would allow gathering in-depth information on the participants' attitudes, feelings, perspective, perception, and expectation of caring for someone on the autism spectrum (Dicicco-Bloom & Crabtree, 2006). The eight-question semi-structured interview provided some systematic structure for consistency across the dialogues towards my research objectives. This semi-structured interview guide was flexible, accessible and rational as it allowed room for my respondents to be spontaneous in their descriptions and narratives. To quote Riessman, (2008), it allowed the participants to "construct who they are how they want to be known" (p.7).

Additionally, probes were embedded within my interview guide to elicit more elaborate or complete responses from the participants. Galletta, (2013) supports this decision to use semi-structured interview guides as she posits,

**"…the process of bringing to the surface the multidimensional nature of lived experience. It responds to an imperative for fine-grained qualitative analysis to open up new possibilities in understanding complicated phenomena often accepted as unproblematic. The semi-structured interview is particularly instrumental in achieving this type of texturing" (p.2).**

Further, Galletta, (2013) argued that the semi-structured interview approach "creates an opening for a narrative to unfold, while also including questions informed by theory. It also leaves a space through which you might explore with participants the contextual influences evident in the narratives but not always narrated as such" (p.2).

Indeed, the decision to use a semi-structured interview provided an opportunity for me to engage in deep and meaningful conversations and interaction with my participants within the research purpose. A total of 15 interviews occurred on face to face basis, and this method provided an opportunity for me to participate in direct communication and interpersonal engagement geared towards establishing rapport and relationship with the participants. Dicicco-Bloom & Crabtree, (2006) state that "the semi-structured interview is meant to be a personal and intimate encounter in which open, direct, verbal questions are used to elicit detailed narratives and stories. The interviewer's task is to obtain information while listening and encouraging another person to speak" (p.318-319).

The interview data that were collected were digitally recorded, each lasting between 45 to 95 minutes and were transcribed verbatim for investigation according to narrative inquiry "procedures and analysis aimed at the scrutiny of social situations, their actors and actions about the narrative" (Gubrium &

Holstein, 2009 p.250). See 3.10 Data Analysis. In other words, the participants and I engaged in the co-construction of the narrative, there were moments when participants will move back and forth with their narrative, and there were moments when this back and forth in storytelling created contradiction, confusion, and misunderstanding; while verbatim snapshots are useful I was also interested in the evidence of my experience from ethnographic observation. I am confident that this method was more responsive and authentic to the objectives of the research.

### 3.9.2 Field Observation

In addition to interviews, the observational data addressed the contexts of narrative production. Indeed, it allows narrative ethnographers to focus on the "social processes and circumstances through which narratives are constructed, promoted and resisted" (Gubrium & Holstein, 2008, p. 256). In this narrative ethnographic study, the interviews with the respondents were triangulated with observational data (storytelling interaction and self-reflection). Certainly, this is a distinctive feature of this approach as the researcher and participant are presented with "a single multivocal text that focused on the character and process of the human encounter" (Tedlock, 1992, p.xiii). To contextualize the narratives I took extensive observational notes while conducting the interviews. For example, documenting the participants' body language. I decided to use these two methods as a way to assure the validity of the research and to help capture a more comprehensive understanding of the caregiver's experiences (Reeves, Kuper, & Hodges, 2008). In addition to being centered on the lives of the caregivers, it also gave due consideration to the engagement of my experiences, perceptions and emotional reactions. I will expand on this later in the chapter.

According to Schensul, Schensul & LeCompte, (1999), participant observation is defined as "the process of learning through exposure to or involvement in the day-to-day or routine activities of participants in the researcher setting" (p.91). In this research, I was able to engage in conversational or storytelling with the

participants while simultaneously engaging in direct observations of the interaction and involvement with the participants. As I mentioned earlier, my engagement with the participants began at the recruitment and continued throughout data collection and analysis phases and finally at a feedback session. Clandini and Connelly (2002) posit that any narrative-focused research is "a collaboration between researchers and participants, over time, in a place or series of places, and social interaction within milieus" (p.20). Throughout this process, I remained focused on the overarching research objective, which was to explore their experiences, perceptions, and understanding of supporting an autistic individuals within the Grenadian social context.

I relied on Singleton & Straits (2005) as the entry point to gathering and recording field or observational notes in narrative ethnographic study. To minimize recollection errors, I recorded my observation of the interviews as soon as it was possible. These detailed recorded observations or field notes accurately highlighted what I observed without any immediate analysis. I documented the date, time, location and setting of the interview. Additionally, I documented participants' descriptions briefly and, more extensively, their behaviours including gestures, facial expressions, and other nonverbal communication and perspectives. For example, if a participant crossed his or her arms or expressed a sigh of relief, these were all recorded in my field notes as I felt it would add contextual depth to the data. I thought it was essential for me also to document experiential data related to my perceptions, impressions, feelings and any subjective reaction to the participant's narrative I had while I was engaged in the fieldwork. Sangasubana, (2011) states that documenting subjective reactions within field observation "may provide clues to biases which might be clouding your observation" (p.570). Further, Tedlock (1991) suggests that it is crucial that researchers "both experience and observe their own and others' co-participation within the ethnographic encounter" (p.69). Finally, as the interviews progressed, I took note of technical issues or methodological notes related to the data collection process; for instance, I encouraged participants to select environments/settings for the interviews that were quiet to

avoid distraction and background noise, which were challenges evident in the earlier interviews.

The collected data (field notes and transcripts) were outlined and organized highlighting the experiences of the participants. To ensure validity and trustworthiness in the data, I asked the research participants for initial feedback (member checking) on the transcripts and memos informed by my observational notes. A total of 8 participants provided preliminary feedback. As mentioned previously, I returned to Grenada after the completed data analysis for further feedback and confirmation. This back and forth approach between the participants and this researcher are essential to consider, as narratives (stories) are not just reflections of experiences in a vacuum. However, narratives involve the interplay and analysis of experience, audience and environment in creating stories (Hutchby & Wooffitt, 2008). Later I will demonstrate reflexivity and consider my voice in the study.

## 3.10 Data Analysis

The following section will highlight the analysis through which the research was developed to respond to and address the research questions. It should be noted that my data analysis process did not necessarily follow a sequential order but worked in tandem with the other research procedures in the production, exploration, and representation of the caregiver's narratives accounts (Mura & Sharif, 2016). Moreover, Ely et al., (1997) suggest that in qualitative research, the analysis is not a linear process, but it is somewhat recursive, where you are expected to move back and forth when necessary. As it relates to this research, Gubrium & Holstein (2009), state "narrative ethnography provides the analytical platform, tools, and sensibilities for capturing the rich and variegated contours of everyday narrative practice" (p.250-251).

Further, Gubrium & Holstein (2009) suggest that the focus of the analysis should be "on the contexts, conditions, and resources of the storying process" (p.262). Certainly, narrative analysis disturbs traditional methodical analysis,

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which has realist assumptions and is often focused on the information collected on the contrary within the narrative analysis approaches. The focus shifts to consider the very construction of narratives and the role they play in the social construction of identity (Roseweld & Ochburg, 1992). As the primary researcher, I needed to be present and reflective about what constitutes appropriate data (the storying process) and how it should be analyzed. More importantly, I had "to remember that narrative work, and narrative environments are reflexively intertwined" (Gubrium & Holstein 2009, p.26). In other words, while in the field, I needed to consider the circumstances that contribute to narrative production and understand how stories are produced and retold especially within the Grenadian social, economic and cultural environments. More specifically, these guidelines below were followed in my narrative analysis process.

Directly after completing each fieldwork interview/observation, I reviewed the recorded audio and documented field notes and briefly wrote up a  research memo on critical insights from my observation of the participant, on important descriptive and as well on reflective information (Groenewald, 2004; Creswell, 2011). Ryan & Bernard (2000) state "themes are abstract (and often fuzzy) constructs the investigators identify before, during, and after analysis" (p.780). Following this assertion, early in the research process, I began to look for, and notice patterns of interest within the collected data. I documented those early patterns.  I then engaged in a process called analytic bracketing. According to Gubrium & Holstein 2009, analytical bracketing is the process of shifting sporadically between the (how's) narrative work and (what's) of narrative environments to make sense of narrative reality. In other words, an assumption is made that language conveys meaning, however analytical bracketing contends that how a story is told is as important as what is said. An account of the content and the form of interaction between the researcher and participant is therefore critical. For example, questions I considered within this framework included: why is the participant narrating their experience in this particular way? What is the purpose of the story?  How have I influenced the narration? How have the others present or the environment influence the narration, or how does

this exact narration fit within the participant broader narrative during the interview process. It should be emphasized that although analytical bracketing is similar to analytical strategies in phenomenological research within the Narrative ethnography approach, it operates differently.

Gubrium & Holstein (2009) argue that bracketing within narrative reality encourages researchers to engage with their assumptions and bias not only at the beginning of the analysis but throughout the research process. Gubrium & Holstein (2012) further state that the objective is "focusing on both the active and substantive sides of the construction process to assemble both a contextually scenic and a contextually constitutive picture of the reality under construction. The objective is to move back and forth between aspects of the process, documenting each in turn and making informative references to the other" (p.6-7).

Accordingly, utilizing this idea of analytical bracketing methodologically allowed me to explore and describe the diverse ways in which autism is constructed or understood in Grenada. More specifically how the fifteen participants describe their experiences (set of stories) of caring for an autistic person or someone that may be autistic and how these personal experiences are influenced and draw from historical, cultural, social, socio-political, socio-economic and lived experiences and when taken together represent the participants' lived realities. Hence, throughout the data collection and analysis process, I was engaged in a constant interplay between the description of the caregiver experiences (personal choices) to the account of the contingencies (internal and external environments) that may have contributed to their narrative reality. I also had to consider how my North American experience and the profession as a trained clinical social worker working within the autism sector might elicit, interpret, resist or co-author the stories being told by the caregivers.

### 3.10.1 Analytical Framework

I applied thematic analysis as the data analysis procedure since it is flexible and because it fits well with my epistemological/constructionist paradigm (Braun & Clarke, 2006). Thematic analysis is described as an approach for identifying, analyzing, organizing, describing and reporting themes found within the dataset (Braun & Clarke 2006). There are numerous ways to approach thematic analysis, see (Boyatzis, 1998; Alhojailan, 2012; Javadi & Zarea, 2016). For this study, I followed Braun & Clarke's (2006) six steps for doing thematic analysis to unpack the shared experiences of the participants' stories on caring for an individual living with or suspected of ASD (see table 2 for a breakdown of these steps).

The fully transcribed interviews and fieldwork notes were read several times to identify initial codes. These preliminary codes were assigned colours on the transcripts to quickly identify commonalities across the dataset concerning the research question.

| 1) Familiarizing yourself with your data | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas |
|---|---|
| 2) Generating initial codes | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code |
| 3)Searching for themes | Collating codes into potential themes, gathering all data relevant to each potential theme |
| 4) Reviewing themes | Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis |
| 5)Defining and naming themes | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme |
| 6) Producing the report | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

**Table 2: Phases of thematic analysis and phase description of the process, (Braun & Clarke, 2006 p.87).**

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After reviewing/ refining the identified codes, a thematic coding framework was drafted. A software package for qualitative and mixed methods research (MAXQDA) was then used for data management, and as new codes were identified, they were added to the coding framework. During this stage of the analysis and following Braun & Clarke, (2006) framework the codes again were reviewed and refined to produce a final coherent thematic summary. The research memos were not assigned codes but were used as supplemental information in the analysis and for triangulation of the data. I must reiterate that the entire methodical process was done over 3 to 4 ongoing consultation with participants (member checks) requesting feedback for validation throughout the analysis of the data (Wang & Geale, 2015). A total of 8 participants provided initial feedback on the data and analysis. The data/themes were revised and refined based on participant feedback before the final analysis and submission. All 15 participants provided input on the final analysis.

As noted above, a few distinct but complementary approaches (narrative inquiry-analytical bracketing and thematic analysis) were used in this qualitative research; this combined approach provided a multi-dimensional analysis for a more comprehensive understanding of the fifteen caregivers' experience providing direct care to individuals with or suspected of ASD in Grenada. To this end, the thematic analysis techniques integrated with my reflection on the narrative reality provided a broad overview (themes) from the dataset, while the narrative approach provided individual stories in support of these themes (Shukla, Wilson & Boddy, 2014). Indeed, Creswell, (2007) suggests that the narrative approach is "best for capturing the detailed stories or life experiences of single life or the lives of a small number of individuals" (p.55). Accordingly, in what follows I conclude with a typology of the narrative analytical method described above. The storytelling process describes the interaction between the participants and the researcher within the narrative environment. This is then understood in relation to the interplay between what is said and how it is said between the participants and the researcher. The analytical practices considers what was said (text), how it was said (performance) and the narrative environment (place) to make sense of the individual and collective stories of the

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participants. *Figure 3* presents a summary of these. That said, the typology is not meant to be hierarchical or evaluative and "as with all typologies, boundaries are fuzzy" (Smith & Sparkes 2008, p.21). However, it is a simple lay out of the process and analytical threads ascribed within this narrative analysis.
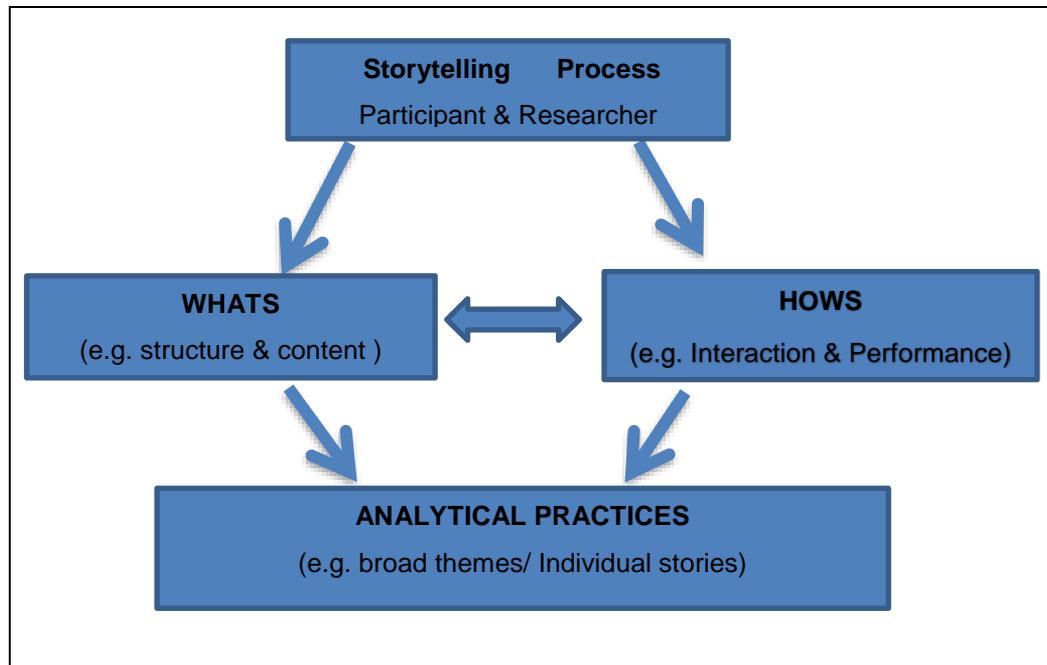


**Figure 3. A typology of narrative analyses**

The next chapter provides an analysis of the discussions/ stories with the fifteen caregivers' inclusive of the themes that emerged from the analysis and the relevant personal narratives embedded within the various themes.

## 3.11 Where do I fit in all of this?  (Self-Reflexivity)

An essential feature of the ethnographic narrative approach is the emphasis placed on the role of reflexivity in the data collection, analysis, production and representation of narratives accounts in research (Polkinghorne, 1995). Reflexivity can be defined as a process of examining oneself considering one's preconceptions and assumptions and its impact on the research process and research relationship with participants (Goldblatt & Band-Winterstein, 2016). This is perhaps better explained by Gouldner, (1971), as cited in Dowling,

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(2006), who claims that reflexivity refers to the "analytic attention to the researcher's role in qualitative research" (p.16). Dowling, (2006) went on to argue that reflexivity is both a concept and a process. As a concept, it refers to the researcher's ability to be self-aware and attentive to consciousness thought out the research course of action. As a process, it refers to the contemplative role of subjectivity including consideration on the researchers' values (parahoo, 2006) and a recognition, interrogation and understanding on how the researchers' "social background, location and assumptions affect their research practice" (Hesse-Biber, 2007, p.17).

Reflexive engagement is particularly important in qualitative research as this approach, when compared to quantitative methods of inquiring, has been referred to as simplistic, impressionistic, anecdotal, inundated with researcher's bias and hence weak in establishing validity within research findings (Buckner, 2005; Patnaik, 2013). In response to these criticisms, an active, reflexive process was necessary to justify and establish credibility and procedural integrity of my research engagement, analysis and finding (Marrow, 2005). Goldstein, (2017), posit "reflexivity requires a deep and critical consideration of one's subjectivity, the psychic material generated from the process may not be fully conscious; thus, our translation of what has occurred will be somewhat inaccurate and certainly incomplete" (p.154). I will now share the general idea of my reflexive engagement and experiences to the degree that seems useful while being mindful that this description does not adequately capture my experiences from the data collection, analysis and reflexive processes.

As mentioned before, reflexivity calls for introspection, a level of consciousness and an acknowledgment that multiple subjectivities are evident within every facet of qualitative research (Goldstein, 2017). As I mentioned before, my interest in research with autistic people seemed to emerge in conjunction with my work as a clinical social worker in a leading Mental Health and Addiction hospital in Toronto, working directly with clients and families affected by neurodevelopmental disorders. I provided support in some capacity including; case management functions, clinical planning and psychoeducation functions. I have heard from these clients and families of the challenges and barriers

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faced, including caregiver capacity, caregiver burnout and broader systemic issues.  Increasingly, as a diasporic Grenadian residing in Toronto, I became motivated and interested in exploring the experience of autistic persons, and their caregivers in the context of Grenada, given the island culture and understanding of disability generally, the inadequate resources and the lack of professional and social services support on the island. I had made some assumptions about what the experiences might be, given the deficits above before even engaging in my research; these and other assumptions continued during the research process. It was necessary for me to take notice and to bracket these assumptions and personal experiences and remain focused on the participants' experiences within those discourses. I did this by engaging in self-reflective practice and by journaling my thoughts and feelings as soon as I became aware of them.

With Narrative Ethnography and data collection method, fieldwork, in particular, it is possible that researcher/ participant boundaries can become blurred (Hammersley, 2006). In conducting my research, this did call for an enquiry into which role I was playing (social work expert vs researcher) in my interaction with the caregivers. There were moments when some participants become interested in my personal and professional life that may have moved beyond the objectives of the research. For instance, during one of the recorded interviews, there was a caregiver who requested my advice on supporting her autistic child. The family was dealing with a stressful situation and needed input on clinical and support service direction.  In the moment, I was very frustrated that I could not provide direction to this family. I was well aware that doing so could have potentially compromised my research and perhaps cross ethical boundaries and on the other hand, I felt I had an obligation as a professional to assist. In this instance, I gently reminded the participant of the objective of the research and redirected her to the Grenada Autistic Foundation for support. There were other moments in the data collection and analysis process where I was confronted with similar internal conflict or tension by responses from participants that did not reasonably reflect my values, experiences and knowledge of autism. In retrospect, what I have found incredibly helpful about reflexivity in my research process is the substantial time spent 'memoing', which

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allowed me to authentically note my immediate observation, thoughts, attitudes and responses to my participants. More importantly, I got a good understanding of how space/ environment/ resources can shape our understanding of disability, in this case, autism.

Although reflexivity does not explicitly address the question of validity (Patnaik, 2013) engaging in the process within the narrative enquiry, in particular, offers a valuable contribution to the inter-subjectivity of qualitative research as there is an explicit acknowledgment of multiple voices including the voice of the researcher in the research discourse. Indeed, I am aware of the contributions of my own subjectivity to the construction of the narratives/stories of the fifteen caregivers with whom I engaged in their experiences and perspectives on caring for someone living with or suspected of ASD.

## 3.12 Ethical Consideration

This study received the approval of the Research Ethics Committee in the Faculty of Arts and Social Sciences and Lancaster University Management School at Lancaster University (REC reference number FL17066-Appendix - G). As mentioned earlier, the participants in the study were briefed thoroughly on the rationale and purpose of the study, and if required further clarification was provided to them. Once the participants had indicated that they understood everything clearly, they were expected to provide informed signed consent to protect them and the researcher (Creswell, 2007). It was made very clear to the participants that their involvement was voluntary and they could withdraw from the research at any stage without consequence. However, participants who wish to withdraw were encouraged to do so within four weeks after taking part in the study to avoid inclusion and anonymization of their data. The data collection methods, inclusive of the time commitment and analysis were described clearly to the participants, so they knew what was expected.

Creswell, (2005; 2007; 2014) suggests that researchers are ethically responsible for maintaining participants' confidentiality, protecting anonymity and for promoting integrity and credibility within their research. In order to

ensure ethical research practice when presenting the findings, all responses were anonymous. Indeed, the smallness of the island has created a challenging task on the anonymity and representation of the caregivers in this research. This is supported by Moosa, (2013) who argued that the "problems of anonymization may be further magnified by distinctive geographical features, particularly the smallness of countries and communities" (p.484). Therefore, I have been very deliberate in providing minimal identifying information to protect the identities of the participants and the individuals being supported; pseudonyms are used as well as the age of the autistic persons were provided.

Given these challenges, participants were also informed that I could not guarantee absolute anonymity but that all reasonable care will be taken to ensure that this does occur. For instance, rather than listing the participant's specific community/ village, I provided broadly the parish wherein they resided and while it was important that I protect the identity of the participants it was equally vital for me that their voices and thick description of their experiences in relation to the context of the research remain fair, evident and authentic within the narrative environment. Also, I felt that it would be important given these circumstances that I engage in constant conversation and negotiation with the participants on issues around anonymity and representation throughout the research process.

The data collected from the caregivers was encrypted (kept private and confidential). Hard copies of any data including field notes and memos were securely stored in a locked cabinet in a locked office within my residence. The audio recording and transcripts of the interviews were stored on my password-protected computer system. The initial data was shared with the individual respondents for review and feedback to ensure transparency and accuracy. The participants were informed that the anonymized data would be shared with my research supervisor if required and in accordance with Lancaster University guidelines, participants were informed that the anonymized data will be kept securely for a minimum of five years after which this researcher will destroy the data.

I explicitly informed the participants that the result would be disseminated to Lancaster University for the partial fulfilment of the requirements for the degree Doctor of Philosophy in Education and Social Justice. Further, they were informed that the results might also be submitted for publication in an academic/ professional journal and, more importantly, will be made accessible to the people of Grenada.

A small compensation was given to the participants in recognition of the time and effort devoted to the study. Within the Grenadian cultural & social context, a small financial contribution for participation in an interview, focus group or discussion is expected and is viewed as a sign of respect by the persons for their voluntariness and worth of recognition. The participants in this study received a modest compensation of $60 Eastern Caribbean Dollar (EC), equivalent to £ 16.88 at the end of the interview and $40 EC (£11.25) on feedback/follow up meetings.

I was determined to respect the dignity of all the participants and to ensure that they did not feel exploited merely as research subjects geared towards my research interest, but as engaged community members who share everyday experiences caring for someone on the autism spectrum and who may potentially benefit from the education, knowledge and insight  gained by participating in the project.

In the following chapter, I will provide an analysis of the data collected.

## Chapter 4: Finding

The purpose of this study was to explore how caregivers in Grenada perceive, understand and experience supporting an autistic person or someone that may be autistic; this was explored concerning the overarching research questions that were outlined in the previous chapter. Moreover, the themes that emerged from this study were not explored as a disconnected set of data, but they were compared within and across the fifteen participants' stories within the narrative reality framework. In other words, the socio-cultural, socio-economic and contextual factors that are unique to Grenadian culture were considered in the scrutiny of the data/stories to inform the themes that follow.

The themes that emerged from the analysis of the data include (4.1) perception of autism, (4.2) thoughts on the caregiving role/task (4.3) supporting the supporter, (4.4) barriers to assistance and support, and (4.5) aspiration, expectations and ideas. Each theme has associated subcategories that will be discussed in turn to elucidate the caregiver's understandings and lived realities supporting someone with ASD. In order to embrace and recount the fifteen participants' stories rooted in their lived experiences, where possible, I have purposefully decided not to revise the excerpts including the Grenadian dialect. The hope is that the unedited and uncensored re-storytelling will be as authentic as possible. How people speak gives voice to their culture, educational background and knowledge. To "correct" the participant's speech will not only lose the essence of their experience but may also signal to them, that their language is deficient and therefore unworthy of being deployed in 'academic speak'. For clarity, I provided an interpretation of the Grenadian dialect where necessary.

### 4.1 Perception of Autism

In the literature review chapter, I outlined that Autism Spectrum Disorder affects individuals and families across heritage, cultural and geographic backgrounds,

and that cultural attitudes about ASD determine how it is understood, interpreted and accepted within various communities. These cultural attitudes will also influence the kind of treatment and services (if any) that individuals and families seek out for support. A constant theme that was evident across the participant narratives was how caregivers perceive autism within the cultural context of Grenada. There is limited information about autism on the island, and this analysis provides some vital information about caregivers' perception and experiences on the disorder, a useful starting point in order to ensure culturally responsive supports and services.

### 4.1.1 Limited knowledge about autism

The concept of autism was one of the themes that consistently came up throughout the interviews. Several participants spoke about initially not being acquainted with or having a primary understanding of what autism meant when it was brought to their attention about the person they were supporting who is suspected or diagnosed with the disorder. Participants spoke about how they become more familiar with the concept. Delphine explained her introduction and thoughts on the concept of autism:

> Well, when I heard it I was thinking is like, what is this autism? I never researched it before, and then it is like when I heard it, I was like okay, my son has this like he has a fault. And I was like, okay, where can I get help and "ah go" and Google it and then I read up about it. I read up a whole article, even copy a whole, about even 10 to 12 pages based on reading and how to go about treating a child that have it, you know. It was a little bit challenging when I started reading it because I was thinking, okay well, my child is different from other kids. My child is not normal and will need extra support; there is still a lot I do not know about autism. my husband and I really want to know more!

Another participant, Charlene echoed a similar thought:

Well before, my first opinion was toward art, to do with art, it did not necessarily have to do with a child being disabled or something. I thought it had to do with drawing or colouring or something like that. Then I began reading online and saw some stuff on TV and realize it has to do with people being slower than normal and kinda different to normal people. I still don't know a lot about this autism thing but I willing to learn more.

In addition, to the relatively low awareness and a rudimentary knowledge of autism amongst caregivers as disclosed by Delphine and Charlene, other participants spoke about the lack of understanding about autism within the school and family context in particular. This excerpt from Dante, a father of two adult males diagnosed with ASD illustrates this point:

Well, I think, when I first heard it, I clearly didn't know what it was. The first time hearing the word I didn't have a clue what it was but then, of course, you begin to do research, and you know, readings and so on but clearly, it was something that was relatively new for us as parents because we had never come across a child prior to that occasion or hadn't participated in any forums or discussions on the issue. So it was something relatively new for us. And in fact, when we began to bring the child in school, that was the first time for a lot of the teacher also coming into contact with the very word itself, much less the whole situation that goes with it. These teachers had no clue how to be supportive. They had no idea what they were dealing with, and even members within our family circle were also unfamiliar with the word or what autism meant.

Samara, a grandmother, caring for her fourteen-year-old grandson also spoke about her experience "ah don't know nothing about this autism they say Walter (not his real name) have and the teachers in the school-worst than me, they do not understand Walter ether." It appears from these quotations that this sense of unfamiliarity with autism does not only influence the experience or lived reality of the individual in the context of the home, but it seems to affect other environments in which he or she may interact. Other participants spoke about

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the confusion they experience in trying to understanding the concept of autism. Aaliyah spoke about her understanding when she first heard the word autism:

> It gave me a feeling of a little 'waw' [muddle] and then I went to research the name online, research what it is like. If I could tell you exactly what it means still, right now, I would not be able to tell you, but then afterwards, I learned and understood how to just be at ease with the situation.

Similarly, Dorsey commented on his understanding of autism:

> It is really difficult raising a thirteen-year child and not being very aware of how to be the best father; the truth is Mr. Leo I do not know my son, I do not understand him. This autism thing does not make any sense to me. I do not understand it at all. Sometimes Dillon (not his real name) is doing so well, and other times is like he in his own world. It have me barzodee [puzzled].

The caregivers' narratives shared above highlight different standpoints on the understanding of autism as a concept; it is evident from these extracts that the caregivers' familiarity with autism is limited and this creates some challenges with conceptualizing ASD. However, it is also evident from these stories that caregivers were eager and determined to learn more about autism by using the resources that were most accessible to them, a point I will return to in section 4.3.

### 4.1.2 Opinions on ASD etiology.

All of the caregivers interviewed commented on the cause of autism within the context of their experience. They remarked that their theorization of ASD is directly connected to their understanding (or lack of understanding) of the diagnosis. For some caregivers, the unfamiliarly and lack of knowledge about autism has fueled some interesting ideas surrounding what may have caused

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autism, ranging from preternatural to natural explanations. For instance, infidelity or wrongdoing by a parent was noted as a reason for someone having an autistic child, Dorsey explained:

> My ex-wife feels partly responsible for Dillon autism, and I think it makes some sense {long pause}. She cheated on me a few times before becoming pregnant with, Dillon this autism thing must be God's penance for her horning me [her unfaithfulness].

Nia had a very relatable story:

> God gave me one piece ah punishment, and I must live with the consequent. I have not spoken to many people about this obviously because I am embarrassed but while I was with Lynn (not her real name) father I was seeing someone else. He never found out but God was watching me, and now I have to deal with Lynn behaviours, as a result, ah bwoy ah [an expression to show frustration].

A few caregivers commented on other preternatural factors as a possible cause of Autism. In their opinion, the likelihood of autism is directly connected to a manifestation of voodoo locally referred to as "Obeah" inflicted on them by an enemy for varied reasons. Ayanna a mother of two said:

> I believe someone pass hand [Obeah] on me and my children some people in the community do not like me and found a way to hurt me and my children.

Khadija disclosed:

> I do not know if this is true, but I was told by Peter (not his real name) mother that someone "do her" [Obeah] while she was pregnant. She told me she got really sick three months into her pregnancy after she accidentally stepped on something in her yard. She believed it was put

there by someone in the village to bring a curse on her, but instead, it was passed on to her unborn child. This is what I was told I don't know if it is the truth!

Caregivers' attribution of autism to preternatural focuses may be connected to their understanding of mental illness which is still taboo on the island and which is sometimes connected to curses and possession by spirits from a past life, and deceased family members as an explanation for the mental health manifestation. Other participants commented on natural or biomedical factors as perceived causes of autism including vaccination, hereditary or genetics, exposure to chemicals and infections, and other environmental factors. Others could not come to a definitive or single rationale for an autism diagnosis, for instance, Dante spoke extensively about measles, mumps, and rubella (MMR) vaccination and possibly genetics as the basis for an ASD diagnosis for his children:

Of course, you would have heard about the MMR. Sometimes I am kind of inclined to want to go that direction. My second son used to speak at about 1 year old calling his older brother by his name; well not fully pronounced, and then of course he started to get his shots and so on, and then all of a sudden, the name calling just dried up, it just dried up, it stopped, you know. Then I heard that my cousin had a son also with autism too, then you wonder if there is some hereditary factors, something genetic. In my boy's case, it may be both; I think there is still a lot of debate, I am unsure on the cause.

Similarly, Malik a father of an 8-year-old male, was unsure on the cause of autism "it could be genetics, it could be the vaccination, and it could be any "dam" thing. I do not know what the cause is but what I am sure about is that Shane (not his real name) is different" [the participant appears to be upset]. Delphine was much more confident that the case of autism in her son was directly linked to medication she was prescribed during her pregnancy and subsequent MMR vaccination:

I am 100% convinced that the medication I took while pregnant hurt Billy (not his real name) and the Mumps vaccination he was given did not help the situation at all!

On the contrary, Candyce, a caregiver for her nephew was suspicious about MMR being the cause of autism and offered her opinion based on her research on the epidemiology of autism being related to the child's parents' parental age, the father in particular:

Of course, there is this thing about the MMR vaccine, which I do not really believe. Somehow, I do not believe that…I mean, I have done quite a bit of research on my own. One of the things, I do not know if it is true or not but, because my sister-in-law was 41 when she had him and his dad at the time was 59. So I know some of the research says, especially if the father is older, you know, that has some kind of bearing on the autistic thing. In my nephew case, I specifically believe it is age-related.

An emotional Cynthia, a mother and caregiver of an adult child, formally diagnosed with ASD, made a startling revelation on what she believed caused autism in her son. Cynthia had lived in North America for an extended period and disclosed that she had received clinical and social support for her son but despite having access to these early supports while in North America, she remained resolute in her belief on the cause of autism in her son. She said:

**Cynthia:** I am being honest with you, I actually say it is the doctors that ruin my baby.
**LE:** The doctors ruin him? What do you mean?
**Cynthia:** Yes, the reason why I say that they give me this epidural the time I had to make Kevin (not his real name) and all my labour pain just cut. I was on this bed there a whole 6 hours waiting, just waiting for the doctor to come. Next thing, a doctor came out from nowhere and just

said, what am I doing here?  And then they took me to the theatre and cut me to take him out.

**LE:** Uh hun, can you tell me how this connects to him being "ruined" as you stated?

**Cynthia:** Yes, from that epidural and all the other medication they put me on and never explained to me. Even while I was breastfeeding him, I was on medication and seeing the doctors eh heh! {Breathe a sigh of relief} Lord have his mercy, {her hands in the air, gazing up to the skies, emotional} so I do not know if it damages his brain, you understand?

**LE:** Uh hun go ahead, tell me more

**Cynthia:** These doctors are criminals they never educate me.  Then I found out; the medication is like drugs! Ohh!  Almost as cocaine and that it can affect the child's brain, so and then I had to stop breastfeeding him and put him on the formula. Then they try telling me different when I confronted them, making me look like I crazy but it was too late Kevin was already damaged.

Cynthia experience highlights two essential points related to caregiver or parent perception on the cause of autism. Firstly, is that their understanding of autism is often context based and might be restricted to what they know or don't know about autism which is indeed a broad and complex neurodevelopmental disorder. Secondly, it is apparent from Cynthia's story that caregiver despite having access to medical and clinical resources wants to be made aware early and may benefit from a clear and straightforward education and treatment plan that addresses the etiology of the child diagnosis.

Other participants spoke about their thoughts related to the cause of autism. Although Khadija retold the account on the preternatural explanation of autism in relation to her cousin as noted earlier, she also wondered about other environmental causes:

Peter was speaking you know. He was speaking throughout when he was one and two years old, and at that time he had nice long hair, and

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then they cut his hair before he begun preschool, and then I realized he just shut down; he just stopped talking. And I was like, why you're not speaking? Now you reach school for you to excel and you are not speaking. Perhaps it is because of the haircut

Indeed Dorsey also spoke about "hair cutting" as a possible cause for ASD, "Dillon is almost 14 years now, but I remember when he was two or three he was very active and outgoing, he had his little struggles here and there, but he was a good kid, but after his first haircut everything changed, sometimes I wonder if that can be the cause for his slowness".The perspectives shared above indicate that caregivers' understanding on what might be the contributing factor to the cause of autism is diverse ranging from genetic, nongenetic and environmental factors. The caregiver's conviction on the cause of autism can potentially influence the characterization, treatment and lived experiences of autistic people within their community and across Grenadian society.

## 4.2 Thoughts and attitude on the caregiving role/task

Many themes emerged from the data regarding the caregivers' thoughts on providing support and assistance to autistic individual or those that may be autistic. It should be noted that a significant number of caregivers recounted both challenging and rewarding experiences in their various caregiving role. These experiences demonstrate a multidimensional and holistic view of the caregivers' accounts as opposed to a single or unidimensional narrative on the caregiving role. In other words, no caregiver experience was entirely negative or exclusively positive; however, both perspectives/ aspects were part of their experiences at some point in the caregiving journey. The stories shared by these Grenadian caregivers on the caring involvement were all unique, yet some commonalities were present across their descriptions.

### 4.2.1 Feeling of frustration

Several caregivers in the study spoke at some point during the interview about the feeling of frustration in the caregiving role. Caregivers used words such as annoyed, failure, letdown and setback to describe their experience of supporting the person living with and/or suspected of ASD. Cynthia shared her thoughts on supporting her son since returning to Grenada:

> Sometimes I really feel like I letdown Kevin, I sometimes feel like a horrible mother to bring him back here to just sit down in the house gazing in space and when I get these feeling it really upsets me.

Nia, on the other hand, spoke at length about her aptitude to be a good mother and disclosed that at times she feels like a failure. Part of the explanation for this according to her account is her inability to discipline her daughter when she is mischievous:

> I feel like a total failure; I cannot even set Lynn straight when she is acting out, what kind of mother am I {kiss her teeth} [expression of frustration].

Some caregivers' feeling of frustration was more directly connected to their own life aspirations, as Ayanna recounted "I am a good parent to my children, but I also have my own personal needs, and when I can't get those met I does feel like they set me back {kiss her teeth} [expression of frustration]. Another caregiver had a similar experience and spoke about the impact of caregiving and the broader family unit, Candyce said:

> I love Lyndon very much and want the best for him, but I also want the best for myself and my immediate family, and sometimes it is a real challenge making time for him, I sometimes see my own children and husband getting upset with me, this responsibility I took on can become very very frustrating trying to find balance.

### 4.2.2 Sense of shock and disbelief

As noted in the literature review chapter, providing care for an individual living with a disability, autism, in particular, can be severe, and families and caregivers can sometimes present with a range of feelings including overwhelming emotions of shock and disbelief as was the case for some of the caregivers I spoke to in Grenada. These caregivers used words such as surprised, unexpected, doubt and uncertainty to describe their experience related to the individual diagnosis /suspected diagnosis of ASD and to the responsibility to integrate the individual living with or suspected of ASD within their various community. Lathan suggests that initially, it was challenging for him to accept his daughter's autism diagnosis but what was most difficult for him were moments of doubt in his fathering role, He discussed:

> When she was three years old, it was very hard on me, that was when she was diagnosed, but I accepted it as my families' new reality. What was much harder for me to accept was that I might not get it right as her father all the time and I was in complete shock how difficult it was to be a good father to this child, trying to ensure her needs were met, I felt utterly incompetent as a father.

One caregiver, Suzette, also noted her feeling about supporting her grandson:

> Rolsten (not his real name) parents provide for him; they send me money, clothing anything I needed for him but let me tell you this, sometimes when I am done getting him ready for school I am exhausted, I am almost 70 years old, and I was not expecting he would need so much help. I will not be able to do this much longer!

For some caregivers, trying to comprehend and negotiate their role as guardians, and their desire for the person living with a disability, in this case, autism can be an ongoing challenge, and this incongruence can compound the feeling of shock, insecurity and doubt as noted above.

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### 4.2.3 Feeling of anger or rage

I have already established in previous chapters that supporting an individual living with autism can be debilitating and can cause physiological, psychological and financial distress on the carer. Some caregivers I spoke to in Grenada spoke about the emotional stress, confusion and bewilderment they experienced in their caregiving role. The following extract from Nia's and Ayanna's narratives demonstrates these caregivers' anger outwardly manifested in the form of rage:

> I cannot take it anymore! Sometimes I ah does just feel to beat up the boy, throw him in some the corner. Sometimes I ask myself, why me? Why me lord? Why do I have to put up with all this shit {caregiver visibly upset in the moment} – Nia

> Sometimes I do yell at Ryan (not his real name) especially when I have to keep repeating myself because he kept doing the same wrong thing over and over or when he just not listening. I do not have the patience; sometimes he gets me really really upset and leaves me with no choice but to scream at him- Ayanna

In addition to being made angry by providing support to the person on the spectrum, a few caregivers spoke about being enraged with the entire family unit by the overwhelming burden of caring, which can become intense. Nerissa shared "I have my days when I curse out my husband, my other children, everybody. I just want to be left alone especially when I am at my breaking point with Angelo (not his real name) behaviours and needs, who the hell is helping me really?" While it is normal to feel angry and it is expected that caregivers at some point may embody anger as a normal human emotion under stressful and difficult situations, what was concerning about the narratives shared was the negative impact it can potentially have on the person on the spectrum, the carer and the broader family unit. However, what was rewarding was the fact that these caregivers are desperately trying to do better. Several caregivers

mentioned being interested in strategies to recognize the signs of anger and more importantly dealing with the anger more constructively: Nia explained:

> Nobody is perfect. We all make mistakes, I do not always deal with my frustration and anger well, but sometimes I take time to calm down and often regret the things I say if you have tips that can help with dealing with this I am all ear.

If caregivers can manage anger more positively and notice the early physiological and psychological signs, it can potentially create a more pleasant and healthy experience for both the caregiver and the person on the spectrum.

### 4.2.4 Isolation and judgement

The fourth theme derived from the participant's account was feelings of isolation and judgement. Caregivers spoke about feeling alone due to the complication and difficulties of nurturing someone on the spectrum, which can at times be difficult to traverse and explain. Cynthia spoke about her experience of isolation and confinement to her home:

> I can't really take him nowhere because of his disability, he has a big man body but the mind and behaviour of a child, he behaves oddly, people look at us funny the few times I took him out so for that reason I mostly stay home, I cannot be bothered.

Cynthia's hesitation to take out her adult son might be connected to the judgement imposed by some community members who may have been unkind or unsupportive to her son's unique needs. Other caregivers echoed this sentiment of isolation, psycho emotional exclusion and judgment by community members "when we are out it is like they see a ghost, I find it very awful and soul destroying, you are already down, but they just have to knock you down further, you really really feel alone" said Charlene. The quotations denote that autistic individuals and their caregivers can both experience social isolation

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which can be a contributing factor to a range of stressful life situations they may experience. Moreover, the prejudice against a person living with a disability and his or her caregiver can make it challenging for them to engage in meaningful relationship and community.

Participants also spoke about the judgment and exclusion they experience within their immediate family and from close friends and remarked that those comments are often most hurtful and painful to hear. They also spoke about not feeling comfortable taking the autistic person to family events such as birthday parties and weddings. Candyce said:

> I took on the responsibility to help care for my nephew because his parents were struggling but I have heard from members of our family that I am allowing him to control my house, that I am allowing him to spend too much time doing this and that and that he will never be better if I continue to allow that, they really annoy me! I sometimes avoid taking him to family limes {events}{particpant visibly frustrated).

Another participant explained:

> Sometimes it hard to take the boys to some friends and family member house because they make comments that sometimes is insensitive, these comments affect my wife mostly  for this reason we are selective with the events we do attend- Dante

It is clear from the above examples that participants at times experience hurtful and unsupportive comments from family members and close friends. These comments can feel like criticism on their parenting and caregiving competence and to an extent, an invalidation of their experience in supporting a person who is not neurotypical and who might require additional and flexible support strategies. These feelings of isolation and judgement, in turn, can affect the autistic person and the caregiver's quality of life in relation to establishing meaningful social relationships and social networks.

### 4.2.5 A sense of faith and community

Grenadians have a strong sense of culture and a very refined understanding of community, and this idea- the sense of community- was also one of the recurrent themes across several caregiver stories. The participants used words such as fellowship, closeness, involvement, relationship and belonging to describe this experience. For example, in the words of Dante:

> …on the other hand the friends and relatives we are close to understand our boys, and those are the relationships we value and cherish. The people we can call on for help!

Or as Delphine explained:

> I have my little tribe, a few friends, my husband and some relatives, the closeness we share helps a lot when I am dealing with stressful situations.

Other participants spoke about their relationship with the faith community in supporting the autistic person. According to Lathan "had it not been for the fellowship of brothers and sisters in Christ I am not sure where I would have been, they have been a source of strength in my family's darkest time." Suzette a grandparent and active church member echoed a similar response:

> If there is one place I can take him and I know he will feel belong is at church, the   other children involve him in everything, when he is at Sunday school I, have no worries.

The above statements characterize caregiver experiences that were more encouraging because of an inclusive environment that embraces and considers the unique needs of autistic individuals. Also, there seems to be trust amongst the caregivers and community members which contributes to a fruitful

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relationship, supportive partnership and the opportunity to engage and encourage participation of the caregivers and the person they are supporting.

### 4.2.6 Experience of love and compassion

All the caregivers spoke emphatically about their love and compassion for the autistic person. Participants indicated that caring for an autistic person although difficult and challenging had allowed them to develop virtue and they believed they are more compassionate in comparison to people that are not caring for someone with a disability, autism in particular. Three participants echoed similar responses:

> I am a better father because of his issues; he taught me patience and determination, it is because of him I know what love is. I have found myself in loving my son. When you have a child that is disabled, it is the only time you really know what kindness really is.- Dorsey

> I tell my sister and them all the time that they can't love as I can. A child with austim will teach you love and compassion and endurance.- Charlene

> I love my grandson dearly, and the more I care for him, the more I know how to understand and see other people struggles.-Samara

It is evident from the extracts above that participants credit providing direct assistance to the person living with ASD to their ability to be reflective and empathetic carers. Dorsey, in particular, spoke about self-discovery in the course of his caregiving, which might mean finding purpose in his life or experiencing moments of fulfillment, clarity and maybe even enlightenment. The compassion, kindness, humility, and patience that the participants reflected in their narratives may also be connected to their value system. Nia spoke about embracing compassion and love when supporting her daughter in the face of challenges:

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Even when she is misbehaving and stressing me out, I sometimes try to understand her disability and try to be a loving mother.

Another caregiver, Ayanna disclosed that loving and being a compassionate parent with limited support and other life stressors is not an easy undertaking:

I am not about to fool myself or anyone else, although I love my child and try my best to be a good mother to my two kids it is at times very very hard especially when you have no dam help and so much other things to get done, at the end of the day I am just trying my best.

Caring for people with autism, especially those that are lower functioning, is an act of displaying kindness and concern. The caregivers I interviewed were able to speak both to their emotional engagement and to the particular support they provide to the person on the spectrum, as Cynthia disclosed "I help him with everything, I have to bath him, feed him everything and I have no problem doing it because I love him." The participants' stories highlight that caring for someone living with or suspected of ASD can be an empathetic and empowering experience for the person, the caregiver and the community in which they live.

## 4.2.7 Recognition and acceptance of the disability

Numerous participants spoke about facing the reality that the person they are supporting would require ongoing assistance given the ASD diagnosis and/or the likelihood that the person may be autistic. They posit that until they recognized the individual need, they were unable to support adequately. Undoubtedly, Candyce's excerpt articulates this point:

It was only after we acknowledged that Lyndon was different and needed additional help to get things done is when things began turning around, we were better able to meet his needs or at best attempt to meet those needs.

Likewise, Lathan spoke about his thoughts and reaction to his daughter's autism and said:

> Like I said, it was tough for me to accept this diagnosis at first, but then I worked through that process, and I am still working through some other stuff, but what has worked for my wife and I is the acceptance that Hannah (not her real name) has some limitation and will need us to help meet them.

Candyce and Lathan's stories illustrate that recognition or acceptance of an autism diagnosis for some caregivers comes as a relief and explanation allowing them to better understand the individual's behaviour and his or her specific needs. The many caregivers I spoke to were all at a different stage in their journey of recognizing the ASD disorder and responding appropriately. Consider the three narratives that follow:

> "Ah know something wrong with her, but like I said I need to know more about it in order to support her better" –Nia

> "I know he has autism; all the signs are there, I hope to have him officially diagnosis soon to get more information on how best to meet his needs"- Nerissa

> "Well Kevin was diagnosed in Canada, and they gave me a lot of information back in the day, I know what he needs, and I know how to support him very well, but I need just some assistance"- Cynthia

As illustrated, the caregivers I spoke with reflected their experience on accepting and recognizing a diagnosis/ probable diagnosis of autism in very different ways. They spoke about how their acceptance and recognition influence their understanding and ability to care for and support the person on the spectrum. Some caregivers had a reasonable understanding of recognizing

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autism while a substantial number of caregivers disclosed needing more information on recognizing the disorder in order to be more effective caregivers.

## 4.2.8 Sense of worth

Many of the participants spoke about a sense of self-worth in how they regard themselves and in their understanding of their strengths and personal attributes. These caregivers spoke at length about the quality they found within themselves that they felt were important in the supporting role. Dante, the father of two young men, made the following comment with an expression of incredible delight:

> "I feel so proud of myself that I can be so very flexible. I can continue to work and provide for my family, be a husband to my wife and a father to my boys even when it is sometimes very challenging".

Candyce commented:

> At the end of the day it feels "dam" good to know you are still standing even if you are standing alone, I am so fulfilled in what I am able to do for this boy.

Another caregiver mentioned the satisfaction she felt knowing that her son can rely on her for support:

> When I am feeding him, cleaning him, hugging him, loving him, I feel the happiness I sometimes can't even put in words. He is my child and how I love and care for him is a reflection on me -Cynthia

A few caregivers also mentioned that a higher power may have designed their caregiving role and that they have a unique responsibility to care for another human being:

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I believe in God, and he said he would never give you more than you can bare, he handed me the responsivity to care for my grandson, and I will do it to the best of my ability and for as long as I can until he removes the responsibility from me"{participant smiled with this expression} – Samara

My God never makes mistakes; he knew exactly what he was doing with Hannah and my hope and faith are built in nothing less but the unchanging word of god. It is my responsibility to be a father to an exceptional child, and I am taking great pride in that responsibility, I will do whatever it takes to be the best. - Lathan

The above quotes speak very clearly to the caregivers' value and self-worth, which are inextricably linked. These participants know who they are as caregivers, but more importantly, they were also able to recognize and acknowledge the difference and contribution they are making in the life of the person they are supporting. It appears that these caregivers are committed to the task of caregiving for various reasons and are prepared to do more and become more of a presence and support to persons on the ASD spectrum, an experience they labelled as invaluable and worthwhile.

## 4.3 Supporting the supporter

I have so far established that caregivers in this study had varying perceptions, thoughts and experiences supporting autistic people and individuals that are probably autistic in Grenada. I was also interested in finding out how these participants in the caregiving role learn to become more competent and confident in providing safe and useful support to the person on the spectrum. Across the data, participants identified four resources that were important in building their capacity, ranging from formal to informal supports. Each support will be discussed consecutively to highlight its contribution to the caregiver's knowledge and skills in supporting an autistic person.

### 4.3.1 The Children's Health Organization Relief and Educational Services (CHORES)

A significant amount of caregivers spoke about the valuable support received from The Children's Health Organization Relief and Educational Services (CHORES) in their knowledge attainment on autism. CHORES is a not-for-profit organization based in Florida and is comprised of volunteers including but not limited to pediatricians, occupational therapists, speech therapists and educators. In consultation with government, healthcare professionals and the business community in Grenada, CHORES provides consultatory and educational programs and services and medical equipment to assist individuals and families living with a disability including various neurodevelopmental disorders. Aaliyah spoke about her experience with CHORES:

> Going to  Chores and them workshops once a month, every third Saturday was very helpful. They taught me thing I can do with him to keep him occupied, and they taught me how to engage with him.

Aaliyah went on to talk about the parenting skills and knowledge she learnt from CHORES professionals:

> We had parental sessions; we did this thing called, Lord the thing deh in me brain and I can't say the word, Conscious Discipline!  We did Conscious Discipline and how to deal with them and through Conscious Discipline, being honest has helped as  an  individual  to grow.

Lathan also spoke about the benefit of CHORES in supporting his learning to care for this daughter but felt that more could be done. He stated:

> Well, when we go by CHORES, they talk broadly about the disorder then they just show like how to exercise her and how to try to talk to her. Yeah, they tell me  what to give her to eat and them things and them but what

I am saying, well, the government should have a place for that. Yes, doing it at home could help as well you know, but I need other help. Even if I do what I could do here now then if it had somebody there, let we say if it is twice a week, then you do a little therapy so, I think she would have been much better now.

Suzette had a very comparable story and in addition, spoke about the psychological support CHORES provides:

The CHORES people were very very helpful to me and Rolsten, they taught me a few exercises for him and the speech lady gave me some ideas on how to speak with him but what I found most helpful about CHORES was the support they gave me to try and cope with the stress from him , I learnt about things I can do to take care of myself, my mind, my body and my soul and to this day I try and put these things into practice. They told me I have to first take care of me to take care of him.

Carlene, a family friend providing direct support to an eight-year-old girl, when asked about her skills and knowledge in the caregiving role spoke with great enthusiasm for the assistance from CHORES and the improvement she noticed in the child:

Well, it is kind of nice knowing that you could actually see progress, like, you yourself will be happy when you actually see her making progress knowing that when she already was with someone and she was not moving anywhere, and all of a sudden BOOM and there you go you have her moving. You feel good about yourself; you feel good knowing that the child is moving as well. I does feel very excited, believe me. I does jump and march like I am going crazy! I understand and can support her better because of the simple things I learnt from CHORES, and now I have her moving.

Other caregivers recognized the sacrifice others made to help them and their child as Malik disclosed "so thankful for all the support we have received from the CHORES volunteers who left their countries, families and responsibilities to help our children and us." Overall, the caregivers I spoke to were all appreciative and thankful for the tremendous contributions from the members of the CHORES team to their skills and knowledge development and for the continued outpouring of generosity to families and local partners towards improving the care and quality of life for people living with various kinds of disabilities and health challenges.

### 4.3.2 Support from School/Educators

Having autistic individual attend school or day programs can be difficult for parents, guardians and school personnel. The participants I spoke with were vocal about the difficulties they encountered engaging with their children's school. However, they also spoke about the benefits the school provides towards understanding their child's behaviours and unique needs. Nia disclosed:

> "sometimes its hard to get any information from the school on how Lynn doing but let me tell you, her teacher is very very good. She help me with information about how to deal with her".

Another caregiver, Narissa, also spoke about the assistance the school provided to her as a parent to her 14-year-old son living with autism:

> "a couple of years ago the school made this booklet for all the parents that have kids with special needs and in the booklet, they very clearly provided an easy to understand explanation of his issues and how to support him safely, to this day I am still using the information and skills from that booklet."

Delphine had a corresponding story:

Billy teacher is very helpful, as much as she can, his teacher will share little information with me that explains goals and things regarding his disability, and with guidelines on how I should respond as his parent, I find them very very helpful as a parent.

Other caregivers spoke about the importance of the parent- teachers association meeting (PTA's) as a source where they can share and access reliable information from school staff and professionals on supporting the person with autism. Lathan shared:

She is in the special school in Victoria {a village}, and when we go down there to the PTA meeting, sometimes it's a waste of time, and then there are times when they share very helpful information on how they are supporting her in the class and things we can try at home, I can tell you she improve a lot eh since we were putting these things into place.

Likewise, Aaliyah stated "well, I try my best to attend all the PTA meetings his school all the time, yeah because that when I have the chance to ask questions about how he doing and get ideas from them on things I can do at home to support him better" For some participants, school personnel/ educators functioned as gateway to much needed additional support for caregivers. Consider this excerpt by Dante:

Our boy's teachers and sometimes some people within the Ministry of Education will inform us on whatever consultants, doctors, whoever came along, whether it is at St George's university or the health centers so we can expose our boys to them, you know. Right now I think there are a couple of doctors from St George's University doing some in-depth studies on autism in Grenada and other learning disorders, so, yes, so you have that kind of support, and I intend to get involved myself to continue to expand my knowledge.

A significant number of the participants had access to the CHORES program I mentioned earlier, and it appears that caregivers learnt about the program from educators as Malik disclosed " I heard about CHORES from his teachers and them, I am glad they were able to get me connected because it was very helpful." Suzette also spoke about the connection with the CHORES program and her grandson's school. She commented:

> My grandson teacher has been a lifesaver; she is the one that connected us to CHORES; I thank god for Mrs. Peters {name change}. I get little tips from Mrs. Peters, and the CHORES people on how to care for him better without the help from people like Mrs. Peters looking after Rolsten would be much much more difficult than it already is.

From these stories shared in this research, it appears that the school/ educators provide useful support to caregivers on general guidelines that can be considered to support an individual with a disability as well the provision of baseline information on autism. Communication also seems to be an essential component towards caregivers' knowledge and skill development which are facilitated within the parent-teacher meetings where there seems to be a genuine desire and need for information sharing. The school and educators also seem to function as an excellent broker resource directing families and caregivers to additional reliable information and health professionals that can further contribute to education and awareness of autism while supporting the individual and addressing the caregivers' concerns.

### 4.3.3 Online engagement

Caregivers spoke about the importance of online resources towards informing their understanding of autism and knowledge towards developing their skills in supporting the autistic person. The participants disclosed spending a great deal of time scouring the internet on issues ranging from what is autism to what causes autism, as illustrated earlier in the excerpts from Delphine, Charlene, Aaliyah and Dante. Other caregivers also reported that online support was

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instrumental towards their knowledge attainment, their attitudes, and the practices they considered to help the autistic individual. Khadija commented:

> When we found out that Peter might have autism I went online to learn more about what it meant, I was trying to find out what we will need to do to help him and I have learnt so much during that process.

Likewise, Nerissa said:

> I have my ideas about autism, but I have found that searching online really helped provide some clarity on it.

Some caregivers spoke about how their attitudes or perspectives about autism were challenged based on what they read online and further stated that it had influenced them in their caregiving role and responsibility. As Candyce explained:

> so with all that I read I realize that something is really out of his control and is really connected to his disorder, so as much as I can I try to exercise patience and I try to get his parents to see that too, but it is tough.

Charlene' story was very relevant:

> It was only after reading online I get to really understand it as I told you it was new to me, now I can support her better because I somehow have a better understanding about how people like her behalf and what they struggle with, I think I am doing better.

Others spoke about how the resources online specifically challenged common cultural beliefs about disability on the island:

The things I come across make us really question the things we see going on here. We as Grenadians really have a lot of work to do, there is so much misinformation about autism and so much stigma against people like my son, and from the research online there experience seems different in places like Canada and the States where there is much support. I really hope you would make a difference here for families like ours. - Nerissa

A few of the participants were more meticulous with their online research on autism and sought support that was evidence-based and more structured. These participants commented that the online information has been beneficial and that the support online allowed them to continue to work and provide for their family as it was flexible and they were able to engage at their own pace.

We did a 12 unit course online on parenting with autism; we did it in our own time, so it did not really have an impact on our other commitments. The course it was about mainly about supports and behavioural management and they provided some basic information and gave the history of autism and so on it was a really good course. - Dante

Well my wife and I did check online, and we did a course with coursera it was free. I think it was with a school in California; I cannot really remember, anyways the course gave a general overview of autism, which was really good and then they went into some sensory stuff I did not really understand, we did not really finish the course. –Lathan

The participants who did the online courses also disclosed that although it was useful, it would have been more meaningful if it were more culturally relevant as Lathan continued to explain:

**LE:** Why did you not complete the course, it sounds like it might have been useful?

> **Lathan:** I would say it was useful, it was just hard to find the time to get it done you know what I mean? Just so much was going on at the time. Plus I did not really find some of the stuff useful; we do not have most of the supports these people were referring to here in Grenada.

Dante stated:

> Although I noted that it was a very useful course it would be nice if our local or regional colleges or UWI [University of the West Indies] develop something more in line with our cultural values as there was sometimes some disconnection because what the course suggested and what we can do as parents with minimal resources and access to professional supports.

Generally, it appears that online resources and support were helpful to participants in Grenada in developing their knowledge, attitude and caregiving practice approach designed to build their skills and to encourage a more favourable outcome for the person living with autism and the entire family unit.

### 4.3.4 Intuitive Support

Some caregivers, the mothers, in particular, reported a maternal instinct that provides an innate knowledge of how they parent or learn to provide support to their autistic child or individual that may be autistic. For instance, participants used phrases such as "it comes naturally to me," "I just get that feeling on what I should or should not be doing" and "I pay attention to my mind," and "I do what I think is the right thing in describing this experience. The participants suggested that the natural knowledge, emotional connection and perhaps close proximity to their child contribute to their decision-making process and caregiving approaches. Delphine states:

> I get this gut feeling; I can tell when something is wrong with him; I can also tell when he is happy. I gave birth to that boy. I suppose, maybe as

his mother, it is something that comes naturally to me, let me tell you when I am unsure about what he needs or what I should do I pay attention to that gut feeling for some direction.

Another caregiver, Nerissa, a mother of a fourteen-year-old male, also spoke about listening to her "gut" for direction on caring for her child:

No one knows my child like I do; no one can relate to him like I can, I understand the little ins and outs about him, I pay attention to my feelings when I need to make decision about him. I am almost always right when I do.

Other participants spoke about abiding by their own decision concerning caring for the autistic individual. It should be noted that some caregivers were prepared to follow their own decision about care or treatment even if those decisions were contrary to the views of professional support including educators and consulting clinicians. The following excerpts from Cynthia and Ayanna's narratives exemplify this point:

I am going to do what is right for my child; whatever feels right for me is what is right for him. You cannot always listen to these doctors and teachers and them; we are the ones that know our children best. – Cynthia

….of course it is nice to have support from these professionals that know a lot about people like my son and they sometimes want to tell you what you need to do to help them but at the end of the day you know your child best, and so you have to take what they tell you with a grain of salt {with some scepticism}.-Ayanna

Participants also reported developing clear parenting and caregiving strategies based on their experience and history of providing support for the individual. Moreover, these caregivers recounted that they recognized that the autistic

individual is dependent on them to meet their physical and psychological needs. It is through this understanding and the personal experiences of providing ongoing care over a period that their capacity is built, thus they can continue to understand and respond to the needs of the autistic person. As Nerissa explained:

> You somehow have to learn to take care of your child; after all, they need you for everything you are responsible for cleaning them, dressing them, cooking and feeding them every "dam" thing. You do these things over and over it becomes second nature and begins to fit naturally, you are able to improve on your parenting skill and can meet the needs of your child better.

Likewise, as Lathan asserts:

> overtime I learnt what I needed to do to support her better, sometimes trial and error sometimes you just know, and because you are so close with them physically and emotionally you really begin to understand how best to support them as a parent, it is not always easy.

The preceding stories demonstrate that participants were open to trusting their instincts in their caregiving role. They disclosed that this awareness has been critical in building their capacity as carers and in their response to the needs of autistic person. Additionally, the participants contend that while it is essential to consider the opinion of specialists in their learning to support the autistic person, ultimately it is imperative that they pay attention to their "gut," too.

## 4.4 Barriers to assistance and support

Another constant theme that came up across the analysis of the data was the lack of necessary assistance and support services in Grenada. Services that play a crucial role in encouraging economic life and meaningful community participation for both the autistic person and their caregiver towards so that they

can achieve a respectable quality of life. Furthermore, assistance and support services can be essential resources to strengthen caregivers' competence, confidence, judgment, and skill in carrying out their various caregiving responsibilities. The fifteen caregivers in this research spoke about the social and economic circumstances they experienced accessing support to assist the person on/ suspected to be on the autism spectrum on the island.

### 4.4.1 Lack of autism specialists

Participants noted the significant shortage of professionals including medical doctors, psychologists and school teachers who are qualified and specialized in autism to help the autistic individual on the island. They disclosed that the shortage and sometimes absence of this professional support make caregiving much more difficult. These participants used words such as a "struggle," "hard," "demanding," "challenging," "tough" and "pain in the ass" to describe those experiences. For instance, Cynthia and Candyce both recognized and disclosed that more formal support, especially from a medical doctor, is important in supporting them in caring for the person living with autism. Cynthia, in particular, spoke about depending on her doctor for help due to her son's complex presentation "I am constantly looking for support from the doctors at the general hospital because it's not only his autism he has a bunch of other illness but sometimes it is like these doctors do not understand how to support us." Similarly, Candyce shared "the doctors, you know, they kept sending him from one to the next, to one to the next as they did not know what the issues were I guess. I think it was the CHORES people that were able to help us with some information and give us some direction we need more doctors who are living here on the island to help us." Some participants also disclosed that there is no specialized training for educators within the school system. The participants shared that caregiving is much more difficult because of this deficit within the school system;

> there was talk that she might have more than one diagnosis, so autism
> and possibly Dandy-Walker Syndrome and apparently this can have an

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impact on how she would learn. I try looking to the teachers for some help on this but none of them could really tell me more about it, if the teaches can't tell you or direct you were to get the information as parents who will?- Lathan

The teachers and them trying they best to help us as parents but they need more training to support these children and them, we could do better as a nation.- Charlene

Another participant, Dante, made a remarkable revelation with regards to the the school systems' support for students with special needs and their families. He disclosed:

Oh man, we had a workshop with our teachers for Special Ed, but the workshop is just two days or four days, and it is not really a specific thing…sad to say we do not even have a school psychologist up to now! I mean we are in 2018 and not a single one!

Likewise, Delphine suggested the lack of psychologists and autism specialists within the school system make it "hard to understand and respond to our children if we do not even have the professionals that really understand the behaviours to help us, who are we to turn to for help ?" The accounts of Dante, Delphine and the others as described above are just a few examples of the vital role of specialist involvement in sustaining and complementing caregivers in their roles and responsibilities for people on the autism spectrum and other disabilities.

## 4.4.2 Delay in Diagnosis

Another theme that emerged is  the delay in getting an autism diagnosis. Indeed, this current theme can be connected to the previous theme that highlighted the lack of autism specialists on the island much needed to give a definitive ASD diagnosis as well as support the person and their family.  Many

participants in the study discussed the issues of delay in getting a formal autism diagnosis for the person they are supporting. The participants spoke about the implications of the diagnostic delay on the individual and by extension the caregiving/ family unit. Consider Dante's story; he explained that his first son was about three years old when he was first suspected of having ASD. He further described that a formal diagnosis did not come until his first son was about seven years old. He noted that in hindsight the delay "worked against my son's developmental progress." Another father, Lathan expounded on the implication of the delayed diagnosis in the context of his experience. He disclosed:

> Maybe if we got confirmation earlier things might have been better for us, we had to wait for such a long time and lost the opportunity to help her when she was much younger

Another participant, Samara shared:

> Well I think before his parents and them did try to find out for sure what his problem was, but up to now, I do not think they were able to get it confirm. I was told there are not enough trained people to do it for us, so we are just waiting still.

On the other hand , the caregivers that had the economic means and access to resources spoke about travelling within the Caribbean region for diagnostic clarification and additional clinical support. As Delphine explained:

> well, we went to Trinidad to find out if it was really autism and to meet with some of the specialists over there…it was a tremendous help, just knowing for sure what you dealing with is a good place to start.

As well, Dante said:

We were not going to wait as long with our second boy for confirmation, so we travelled to Barbados to meet with some folks there that had extensive experience supporting people with autism. My wife and I made the decision that we needed to know early to put the proper supports in place very early.

The majority of caregivers in the study continue to support individuals that maybe autistic and that are not officially diagnosed. They reported that the uncertainty around the diagnosis could be a stressful and aggravating experience. Moreover, while there is minimal support for autisic people living in Grenada, a confirmed diagnosis is not necessary to access the limited supports available as I have outlined in previous chapters. The caregivers supporting the person that may be autistic reported that knowing for sure if it is autism will give them some clarity and that it might encourage them to explore more learning and understanding about the disability. For example, Nia related "it will be nice to know for sure if it is really that he has so I can really wrap my head around it." or as Malik explained " well it might help to know what going on, so if they can give me some more information and confirm it will help because we will know for sure what we dealing with". On the contrary, a few participants explained that it was not relevant to them to have the diagnosis confirmed because they "were sure what the problem was already"  and did not believe there was value in confirmation of ASD when supports are minimal. However, these participants reiterated that putting support in place might be beneficial to improve the outcome for the autstic person and their caregivers.

### 4.4.3 Insufficient and inadequate structural support

Almost all the participants reported the difficulty they face in accessing services and supports for the person on the spectrum in Grenada. In particular, the participants from the rural villages (St. Patricks, St. John's) reiterated this difficulty given the far-reaching environmental and infrastructural challenges in those communities, including for instance limited access to reliable road network and transportation which makes it difficult for caregivers to take the

autistic person to medical appointments and day program activities. Indeed, these caregivers emphasized their dissatisfaction with the current structural support on the island.

> The system we have here really "shitty" not enough support in the schools, no support in the community, no support for us parents, like I am not sure what the government and them intend to do about this. –Nia

> Up here [St Patrick's] we don't really have much programs in place for these children and them, they try their best in the schools but sometimes even that can be an issue, the little supports that are available are mostly in St Georges we need a better system in place for these things.- Nerissa

Likewise, Charlene, who lives in a rural community in the parish of St. John also spoke about the nature of the social/ health and education sector:

> She is not officially diagnosed with autism as yet, the last time I checked, the person said that they have to be sent down to SGU [St George's University] to be fully diagnosed, even to access other professional help we have to travel to St Georges for the support, the better schools are also in the city. We need more support in Grenada, Yes! However, what we also need these center closer to the individual everything does not need to be done in St George's.

Charlene's story poses an ongoing challenge for autistic people and their families in Grenada where there has been minimal success in promoting independence and social relationships since there is a significant lack of choice and control over limited supports and services which are mostly available in the capital city, St George's. Other caregivers spoke about other structural barriers that hinder meaningful participation for the autistic person and their family. For instance, some participants spoke about the lack of access to public transportation as a significant structural barrier to social inclusion. Caregivers spoke about the frustration they experience when they need to take the autistic

person or individual that may be autistic to specialist appointment and other social events, Ayanna explained "it does be real hard to use public transportation with him to see the doctor because of his behaviour I don't feel comfortable taking him on the bus" For this reason, caregivers like Ayanna have resorted to more expensive methods of transportation. Ayanna continued "sometimes I have to hire people to take us to these appointments or to take us to the city." Another caregiver echoed this experience. Suzette disclosed:

> Even if you want to get this children more involve it is a challenge, first off there is hardly any support in this community and when you do plan to take them to the programs in St Georges getting them there is an issue because the buses are unreliable and you have to rely on the help of friends or family which can be an inconvenience or have to pay big money to a private transportation.

For caregivers and autistic people, these aforementioned structural issues can function as powerful barriers to community engagement and full inclusion. On a very practical level, these environmental barriers affect the day to day functioning of the autistic person, and their caregivers limiting their independence hence compromising their quality of life or as in the words of Delphine "we just want to be like every other normal family in Grenada, we want to go to the beach and the waterfalls like anyone else and to do so without all the drama and stress, many people in this country really take things for granted until they have a special child as we do". Indeed, the issues that the caregivers highlighted are exclusionary and rooted in the marginalization of people living with disabilities and their families, and as Delphine articulated, the hope is that Grenada will become more diligent in recognizing the lived experience of those living with disabilities including autism and will provide more opportunities for more meaningful social, cultural and economic participation of these individuals and their families within their various communities.

### 4.4.4 Financial barriers

I mentioned earlier that access to support and services are essential for autistic individuals, and their caregivers, to ensure improved quality of life and positive outcome. Despite this, and in addition to the other difficulties mentioned concerning accessing services and supports, the caregivers in Grenada reported limited financial resources as a barrier to accessing the help and support they require to meet their full potential. Further, the caregivers emphasized that financial barriers pose personal impediments. There are also systemic barriers that can often limit or prevent their access to the limited support and services available. On reflecting on the experience of financial challenges, Suzette commented:

> There is not much money to get things done, and it is hard to look into getting a professional help when the little money you have is needed for medication and to buy pampers. The Government gives me $100.00 (£28.24) and he is on two medication, one cost $56.00 (£15.94) and the next one is $21.00 (£5.98) they last him like three weeks, and the pampers cost $79.00 (£22.49) for 11 pieces. It is costly

Another caregiver had a very similar story and commented on his family experience:

> **Lathan:** financially it is a lot on us at the moment, take for instance we need to buy Epulim Syrup which is about $122.00 for the bottle, and it does not even last   for three weeks
> **LE:** It sounds expensive, do you receive some kind of drug coverage?
> **Lathan:**  Yeah it is very expensive and no I do not receive any coverage, there is a government dispensary but the joke is the medication is never in stock, and so there is no help, I have to pay the full price and on top of that you still have to buy diapers which will cost you an arm and a leg [very expensive].

> **LE:** Thanks for sharing and being so vulnerable, so these personal financial commitment towards your daughter wellbeing does it take away from other things you may have considered in supporting yourself and/or your family?
>
> **Lathan:** Oh yes! I would love to take her to more speech therapy, but if we have to go back, we have to pay $150.00 for a visit and then every other time is pay. They should have something in place for that.

Suzette's and Lathan's narratives provide a clear picture of the financial strain they experienced in trying to provide day to day care and support of the autistic person. It is also apparent from these stories that government funding and support is inadequate, limiting access for the autistic individuals and their families even further. A few caregivers spoke about incurring additional cost to access private services and noted that they were left with no other option because they want what is best for their child and their families, consider Delphine story, for example, she said:

> Even if my husband and I go broke trying to get the best support for my son, it will be worth it all, at the end of the day he is my child, and we have already decided that we will do whatever it takes to make his life the best it can be and will ensure that we continue to inform and educate ourselves.

On the contrary, several other caregivers spoke about feeling inadequate, ill-equipped and lacking full competence as caregivers; they claimed that this deficit is due in part to the service gaps and lack of financial support for the autistic person and their families within the health, social and education sector across the island.

> With all this talk about autism these days you would think the government will be interested in helping families like ours with resources to help raise these kids but nothing, why can't they help pay for a

program or why can't they give us more support at home or something? What a shame! –Dorsey

no money in the school system, no money in the health centres, "not ah dam thing," it is like we are expected to do it all on our own, not sure how when we can do our best when as parents we are not even sure – Nerissa

It is unknown the number of people living in Grenada with an autism spectrum disorder diagnosis however, what has been established from the participants' narratives is that program and services across the island, especially in the rural communities are scarce, and families and caregivers are worried and unsure about how to support the person with special needs requirements. This was mainly, true for caregivers and families with lower economic capital who are unable to access any private support and assistance to aid in the caregiving role. Overall, these findings highlight the impact of inadequate social, political and economic capital on the lived experiences of caregivers supporting people with ASD in Grenada.

## 4.5 Aspiration, expectations and ideas

The caregivers I interviewed in this research project identified a number of needs and intervention that they thought would be useful in the caregiving role, to reduce their stress and burnout, enhance their coping and emotional skills to deal with anger and frustration, and improve their knowledge about disability, on autism in particular in order to improve the quality of life for themselves and the care recipient. Although these findings are presented in sections below, it should be noted that the caregivers did not identify a single need/ intervention as most essential but across the narratives, they acknowledged that a multicomponent and or intersecting approach might be most valuable in supporting them in becoming more competent and confident caregivers, for instance, having access to both psychoeducation and support groups. The hope is that with adequate supports/interventions caregivers will encourage

safe and effective care practices to the person on the spectrum thus minimizing risk and oppressive practices.

### 4.5.1 Enhanced Social Support

Several caregivers identified the need for an increase in the flow of support for autistic people and their network of support which includes the caregivers, educators, health professions and chosen support persons. The participants commented that attempts need to be made to improve the quality of the relationship among this network to continue to mobilize autism supports. Nerissa, a mother of a fourteen-year-old boy, shared:

> I think it important that everyone that is involved with him is on the same page, sometimes A don't know what B is doing and as his parent, it is very frustrating. So, my hope is that some system can be put in place that could make that happen…. kind of like a meeting where we can all talk about what I am trying to deal with.

Correspondingly, another parent, Malik spoke about what he believes needs to happen to enhance the participation in the community and support outcomes for the person living with autism, and the caregiver:

> Well if the teachers and them and the other people that helping him can come to the table and talk about what his needs are, it will help us a lot. Two heads are always better than one, and so if they all come together, I think we will make more   progress with him. We probably will better be able to support him because we may have more ideas and things to try.

Some caregivers spoke more specifically about the kind of enhanced support they require in order to address caregiving burden. For Aaliyah, it was important to have the opportunity to meet other caregivers:

Meeting people with kids and I think dialoguing with the parents, talking about their experiences with their child…. I never liked talking to people, but recently, I have come to a point now where I need to talk a little more because I know I am stress and I think if I am able to talk to other parents with a child like mine that it might help.

Charlene commented, "it will be nice to get a break from time to time, and it would be nice if we can get someone to come into the home and help us take over so we can get to meet with other parents or maybe just do something for themselves." Likewise, Cynthia emphatically shared "In Toronto, there is respite care for families, and there are many programs for the child with special needs, the government here in Grenada needs to consider establishing a centre for families and people with disability, it is about time!" Although some caregivers recognized the value of caregiver respite and/ or caregiver support groups, they felt that greater focus and additional support should be given to educators and the school system so that their children can be better supported. Candyce disclosed:

while I will love to meet other parents to talk about our experiences, I feel what is more important is giving the teachers the support they need, so maybe it would be good to provide a teacher aid in the class to help support child, I think in the end it would be better for the child and for us parents.

Khadija agreed and spoke more extensively about the benefit and importance of social support within the school system and the potential positive psychological impact on the caregiver:

I think if we are able to get teachers more support in the classroom it will help us as caregivers….I for one will be much more comfortable knowing that the teachers have all the resources they need to teach Ziggy [not his real name]. We need more teachers in the classroom, we need support people in the classroom, and we need items in the classroom

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that can help these children. When teachers are better prepared to teach, they are then better able to support them and everyone will benefits, the child, the family, everyone.

In addition to building stronger inter collaborative relationships amongst support networks, establishing caregiver group, respite options and providing resources to educators designed to improve the well-being of the person living with ASD and their families; participants also highlighted the importance of providing and enhancing training for the entire support network in ways that they can be more supportive, for instance, consider this narrative by Cynthia that summarised these ideas thoroughly:

> A lot I have to change, I think first of all you need to go to the schools and educate them because not all children with disability require the same kind of help and let them know not because….. this child has a disability, you should put him in a corner and categorize him and say he's not normal like everybody else. These teachers should encourage others to play with them you know, play with them the same way, you know, talk to them the same way. I think teachers need better and more creative ideas to teach these children. We as parents also need more training, we need more support groups, we need more centres on the island, we have to start somewhere, and I think training on supports is the best first step.

The present research suggests needs and interventions explicitly that the caregivers in Grenada recognized as meaningful social support that may reduce the negative experience of providing care to the person on the spectrum.

## 4.5.2 Financial support

Elsewhere in the chapter, I underlined the impacts of financial barriers on caregivers and the person with the lived experience of ASD. Caregivers in the

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research also spoke about the need for financial assistance to help the autistic person with activities of daily living as well as with community integrations. Nia suggested:

> We need financial help from the government, Lynn [not her real name] needs a lot of medication and things, and I cannot afford to buy these things all the time, they should really provide some assistance.

Another participant, Dorsey shared:

> I am a single father with four children and let me tell you it is not easy. I am doing the best I can, I work hard to provide for my family, and I am not asking for a handout, but any additional help the government can provide will really help me out.

In addition to the point on the request for assistance from the government to help with caring for the person living with ASD, some participants spoke about seeking assistance from private and Non-Government organizations on the island.

> I find, and I does always say, that the government cannot do everything. I think them hotel owners and all these business people that making good money off the backs of we working Grenadians can help support people with disability –Aaliyah

> It has some establishments on the island that donates to disability causes but I think more can be done, there should be greater outreach from the people in social services to reach out to that community and help with organizing help for them disable people especially them with little or no income at all- Candyce

A few participants felt that there is a role for the church in providing financial assistance for families and people living with special needs. Lathan shared his ideas:

> Our church communities can do more to support us, families, don't get me wrong, they are providing support, but I think financial support can also be provided, maybe take up special offering or plan some special concert and donate the money to families in need as there are many especially here in St. Andrew's.

Another participant, Suzette shared a very similar thought:

> I am very active in my church, and I take Ralston [not his real name] with me all the time, it has other people at the church with special needs as well, I find the church can do better with supporting us with some money to help, maybe even sponsor to help get them some professional help.

Several other caregivers shared stories of being unable to work full time and/or not being able to work at all because they are providing ongoing caring for the autistic person. This was the main reason for the request for more financial support. These caregivers emphasized that they are very much willing and able to work but are unable to do so given the caregiving responsibility. For instance, Cynthia shared:

> You think I want to sit down home? No! I want to work but I cannot, so this $100.00 the government giving us a month is not cutting it much more money is needed to provide proper care for my son.

Moreover, as Ayanna disclosed:

> I cannot work because of this child! I had a job and got fired because I always have to leave work because of her. It's not that I am lazy and

don't want to work, I want to work! I even want to go back to school. I really need more help with this child.

Another participant shared some exciting idea on collaboration through which caregivers may be able to receive subsidized programs and services for the autistic person. Aaliyah mentioned:

Social services and them, can come together with families and work out something because these children and them they need proper health, better caring. So when we take them to see the doctor have a system in place where you do not have to pay the full amount money for medication or glasses or whatever, so for example if they tell you the bill $100 (£28.46) you pay $50 (£14.23) and the government or the organization pay the next $50 (£14.23). They need to meet us, parents, halfway.

Participants in the study claimed that these opinions shared will give them more options to access services and supports to "make ends meet" and will relieve them from the enormous financial pressure that they are currently experiencing.

### 4.5.3 Advocacy and awareness

Another theme that was common across the narratives was the notion of advocacy to build the capacity of the caregivers to include and support the autistic person fully. More specifically, participants spoke about the need for government, businesses, organizations and communities to adopt policies, practices and attitudes that affect the person on the spectrum, and their families, and the need to ensure that they are respected and valued and that they can receive useful supports and services based on their need and preferences. As it relates to the government and advocacy efforts, participants spoke about the need for law and regulation changes. Dante stated:

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I think there is a need for more policies and legislation to protect and support these children…our laws, our mental health laws as a whole needs revamping. Our Mental Health Act I think was established in 1801 or 1901 or something like that definitely over 100 years old. The government has tried over the years, but we still have not been able to make any meaningful change.  So I think our laws because it still refers to these children as lunatic needs to change first before anything else.

This idea as suggested by Dante was supported by several other participants who also recognized that the involvement of Government was essential to address the issues faced by autistic individuals and their families, on a national level. Further, the legislative support from Government can bolster quality and effective laws that could potentially influence and encourage clear, reliable and credible guidelines to support people living with various kinds of disabilities and their families. Other participants spoke about the role of businesses in autism advocacy.

Well, even if you go in business places most of the time they do not have thing required for people with special needs. They need all them things and them in places.  For example, a business can support local autism education initiatives by sponsorship, make autism more visible in the workplace. - Lathan

Delphine shared:

Local businesses for sure can help with autism awareness and advocacy, last year a few got involved in the "light it up blue" campaign, (spearheaded by the  Autism Speaks orgnization, the aim is to foster understanding and acceptance for those with autism by wearing something blue) and it really started a conversation on the islands, I think more of these businesses should get involved with things like this may be in collaboration with the schools to bring more awareness.

As it relates to organizations and their role within autism awareness and advocacy on the island, the participants almost exclusively spoke about the Autistic Foundation of Grenada (AFG), a non-profit organization whose vision and mission is advocating for individuals and families living with Autism spectrum. Aaliyah disclosed "my involvement with AFG is very helpful, we are like family, and they really care about getting the concerns of family heard" and Charlene said "I was not sure about joining that foundation, but I am glad I did, every year we host a public education and health outreach forum about autism and other disabilities, and I find it's a good way to educate the public." Lastly, participants spoke about the role of community members in creating safe and inclusive spaces for people on the spectrum and their families. Lathan said:

> Sometimes when we go out we find people laughing at our child, there is a great need for more public education about disability, many people still don't have an idea about what this means.

Cynthia commented on a time for change:

> So this is what I think they should do.  Put it more, advertise it more on the T.V, let the public know, put it in the newspaper, put it everywhere. It feels like everything sealed down; we need to take off the seal on mental health and disability in our society.

Moreover, Dante remarked:

> John public needs to be brought on board but I think a good place to start is with   our schools as low as the primary schools, they need to have more information and education on disability and mental health then we can have some community outreach, maybe with the support of our churches and community groups.

Increasing awareness and advocacy about ASD was vital for these caregivers as it was identified as an essential step in creating change for the person with

ASD, families, caregivers and communities. This can help to promote their understanding of the disorder and increase their education on treatment and services that may be beneficial.

### 4.5.4 Goals, Hopes and Dreams for the Individual

I was also interested in getting a sense of the participants' attitudes about support and to further explore from the perspective of these participants what they believed was needed to improve the quality of life for themselves and the autistic person. In addition to the themes that I have already outlined, above most of the caregivers shared stories about their hopes and dreams for the person they were supporting. The caregiver's responses were embedded somewhere in their attitude and understanding of autism, on disability in general and within their belief system. These caregivers had definite goals, hopes and dreams for the autistic person. Consider Nia who expressed a certain hope for her daughter:

> I want her walk, talk and have a better life like a normal life like everybody else!

Likewise, Ayanna shared "I just want him to have a normal life and find a good group of friends" and for Dante he had hope that his "boys" his firstborn in particular will have some opportunity to be more independent, he stated "I hope one day with all the help and support we are giving him that he will be able to be more free to make good decisions for himself and live the life he wants without our full involvement" Some of the caregivers also had hopes and dreams that the autistic person will one day be able to get a job as they believed the person had some very valuable skills which can be applied in the workplace. As Aaliyah pointed out:

> Although Rob is fifteen I hope one day he will be able to get a job with some company or something, he is very good with his hands and with details and will be good at jobs that require that.

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Similarly, Khadija shared:

> Of course, Peter has his challenges, but he also has some really good strengths, I really pray that one day we will have some places here where he might be able to get a job with some support to bring to light all this wonderful strengths.

Some caregivers found it difficult to articulate and realize their hopes and dreams for the person on the spectrum. Cynthia shared this narrative:

> Sometimes I cried because it's like I have a child and I don't even know what I want for him, then sometime afterwards I said you know what, I would like him to be able to take care of himself in society and be able to say no and yes, and stand up strong to what she wants and need say no, I cannot tolerate this or no, I wouldn't tolerate this.

Moreover, Candyce stated:

> I do not know! I kind of worry about him and I am not sure what his future will look like, I am not sure how the other people cope but I kind of worry about what will happen when we are not around. What's going to happen to him? What provisions will be made for him?  It is kind of worrying. So I hope he will be able to find a home and people that would be able to love him the way we love him when we are no longer around.

The participants had different perspectives on what hopes and dreams meant in the context of the autistic person, and what was interesting from these findings was that the hopes and dreams identified by the caregivers could be associated with the hopes and dreams of caregivers of individuals that are neurotypical. However, the caregiver's narratives did not shed light on the desire, interest and preference of autistic persons concerning improving their quality of life and their place within social norms and expectations.

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In this chapter I provide narratives from the fifteen caregivers to explain the lived realities of supporting an autistic person. The stories that were shared were embedded within five main themes including (1) perception of autism, (2) thoughts on the caregiving role/task (3) supporting the supporter, (4) barriers to assistance and support, and (5) aspiration, expectations and ideas. In the following chapter I will describe and analyse the key finding from this chapter in relation to the overarching research question and in relation to the literature.

## Chapter 5: Discussions & Conclusion

## Introduction

This initial exploratory study has contributed insight into the perception, knowledge and lived experience of caregivers supporting autistic individuals or people that may be autistic in Grenada, an area which was previously unexplored. The study was situated within the constructivist ontology and used a qualitative approach, oriented toward the interpretivist epistemological position to understand and explore fifteen caregivers' lived experiences (Soini, Kronqvist, & Huber, 2011) & (Gubrium & Holstein, 2009) *see* Chapter 3 for details. The findings of this research have been presented in detail in the previous chapter, and a schematic summary of the research findings is provided below (see Figure 4). This schematic diagram is intended to convey a simple visual representation of these findings in this study.

This chapter contains discussions to help answer the research questions:
1. What were the lived experiences of caregivers supporting Autistic individuals and/or persons that may be Autistic in Grenada?
2. How did caregivers supporting Autistic individuals and/or persons that may be Autistic conceptualize these experiences?
3. How did caregivers learn to become well-informed to support Autistic individuals and/or persons that may be Autistic in Grenada?
4. What further support did caregivers identify they need?
5. What recommendations did caregivers supporting Autistic individuals and/or persons that may be Autistic suggest is needed to improve the quality of life for themselves and the autistic person?

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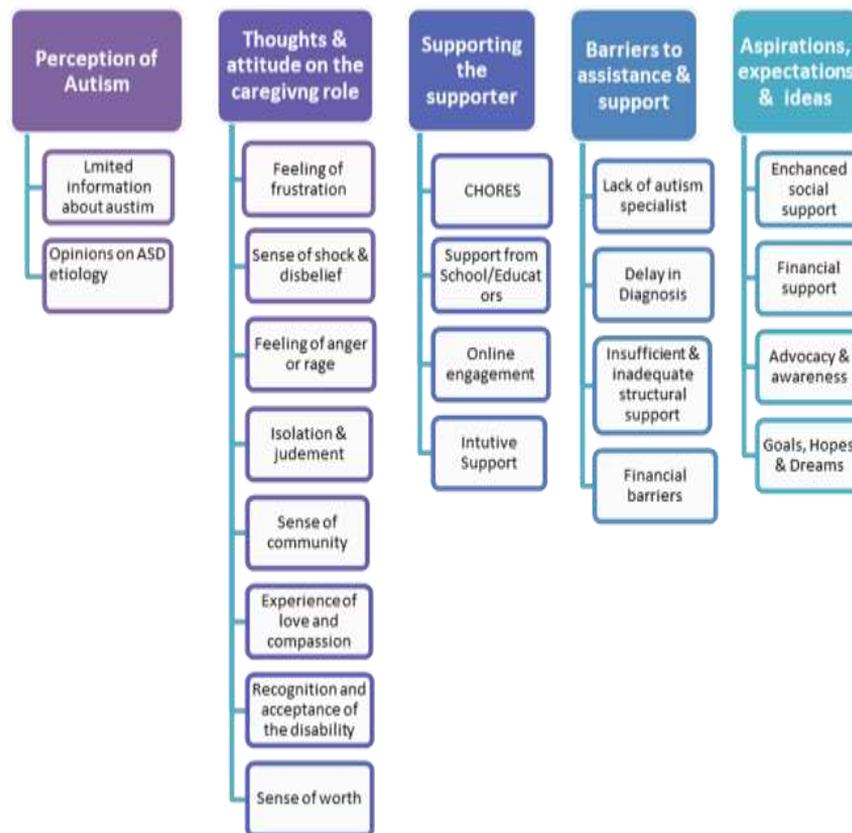
**Figure 4: Schematic summary of research findings**

These overarching questions will guide the discussion, and the research findings will be discussed in relation to the existing literature in the field. Although each theme was discussed individually in the analysis, in this chapter, most will generally be considered collectively due to the interconnectedness of the participants' stories around their perceptions, conceptualization and experiences supporting someone on the Autism spectrum. Throughout the research process (data collection, data analysis and participant feedback), I was sure to remain reflexive of the role of narrative work and its environment in the construction of narrative reality. For example, remaining aware that the process of storytelling and re-storytelling are often influenced by "broader terrain of narrative reality" (Gubrium & Holstein, 2009, p.27). These include how storytellers decide to assemble their stories and how the activation of storytelling may be influenced by the audience, social setting and/or culture environments. Indeed, the stories shared by these fifteen participants are a reflection of their environment towards narrative production on autism

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discourse and the caregiver experiences within the context of Grenada. Later, I will offer a discussion on the reflection, limitation and future research direction of the study and the implications for policy and practice.

**RQ1. What were the lived experiences of caregivers supporting Autistic individuals and/or persons that may be Autistic in Grenada?**

**RQ2. How did caregivers supporting Autistic individuals and/or persons that may be Autistic conceptualize these experiences?**

**Conceptualization of the caregiver experience**

The first two overarching research questions focused on the caregivers' perception, conceptualization and lived experiences supporting an autistic individual and/or a person that may be autistic in Grenada. Research on the caregiver experience supporting an individual living with a disability or mental health challenge is sparse in the literature across low- and middle-income countries including the Caribbean region (Wainberg, et al., 2017). It was unclear how the caregiving role for an autistic person is expressed and experienced within the Grenadian cultural context. Empirically, the findings suggest that Grenadian caregivers presented a range of thoughts, feelings and behaviours in providing support for an autistic individual. Some caregivers felt overwhelmed in their role and reported some negative experiences, including frustration, devastation, disbelief, anger, rage isolation and judgement. These important findings from the caregivers in Grenada is consistent with other studies across the globe that found that caregivers of individuals living with autism experienced significant stress and challenges in caregiving (Hayes & Watson, 2012; Khanna, et al., 2010; Stuart & Mcgrew, 2009).

Moreover, and more specifically some of the negative experiences shared by these caregivers in the research were directly connected to the responsibility of supporting the autistic person, whom they felt challenged their competence as parents and/or as caregivers given the unique needs and support needs of the

autistic individual. Some caregivers disclosed that in the process of caring, they may have experienced caregiver burnout and that it impacted their wellbeing and in some instances, the entire family unit, including the autistic person.

Across the literature, depression, anxiety, other mental and physical concerns are listed as some of the outcomes of caring for someone with autism who may require more time, effort and patience to nature and support (Bromley et al. 2004; Hamlyn-Wright et al. 2007; Khanna et al. 2011; Kuhlthau et al. 2009). Interestingly, the caregivers in this research did not explicitly report on above psychological and physiological challenges as significant problems they experienced. The social stigma that is attached to living with mental health and disability across the Caribbean region may be responsible for the self-silencing these caregivers experience (Gopaul-McNichol, 1993; Arthur, et al., 2010; Mascayano, et al., 2016). Indeed, many individuals and families in Grenada are reluctant to speak out about disability and mental health issues in particular for fear of being labelled as "crazy," and so, families, caregivers and individuals continue to live in silence, pain and exclusion and do not access the treatment and support needed to live a full quality life.

Other caregivers spoke about the disappointment they felt as they had envisioned a very different life for their child/person they are supporting. These experiences as shared by these Grenadian caregivers are similar to other studies from other parents and caregivers across the globe, see for example (Altiere & von Kluge, 2009; Chamack, Bonniau, Oudaya & Ehrenberg, 2011; Koydemir-Özden & Tosun, 2010; Ludlow et al., 2011; McCabe, 2010; Neely-Barnes et al., 2011; Samadi, McConkey & Kelly, 2012; Depape & Lindsay, 2014).

Moreover, in line with other findings such as (Bayat & Schuntermann, 2012; Bekhet, Johnson, & Zauszniewski, 2012; Ilias, Cornish, Kummar, Park, & Golden, 2018), many of the Grenadian caregivers reported relentless strength, resilience and positive experiences supporting the autistic person. For instance, caregivers reported that the hardship and difficulties of caring for an autistic

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person on the island have resulted in some satisfactory outcomes including personal growth and a collective understanding about caring for someone with different needs. The data suggested that community, religion or spirituality to be specific was necessary for some of these caregivers in the supporting role. This finding seems to echo the research by Phelps, Mccammon, Wuensch, & Golden, (2009) who found that while caregivers experience more stress than enrichment in the majority of life domains, that their religious and spiritual support has contributed to more positive experiences or enrichment than stress.

Other caregivers in the study reported experiencing difficulties, while they simultaneously disclosed feelings and experiences of love, compassion, gratitude and self-worth in the caregiving role. Wikler, Wasow, & Hatfield, (1983); Yatchmenoff, Koren, Friesen, Gordon, & Kinney, (1998) and Phelps, Mccammon, Wuensch, & Golden, (2009) acknowledged this duality (positive and negative) of the caregiving experiences. Indeed, to focus exclusively on the problematic or challenging aspects of the caregiving experiences will not fully capture the fullness and lived realities of caring for an autistic person. The finding from this research suggests that participants in Grenada acknowledged both encouraging and undesirable experiences in their respective caregiving role and suggested that a comprehensive approach, including community involvement, should be taken into account when engaging and supporting carers and families.

**Perception of the cause of autism**

Although the origin of autism spectrum disorder (ASD) is unknown and there are unanswered questions on the etiology (Rapin & Dunn, 1995; Yenkoyan, Grigoryan, Fereshetyan, & Yepremyan, 2017); this study also explored caregivers' ideas regarding the cause of autism within the context of their experience in Grenada. It should be reiterated that the caregivers theorization of autism was directly connected to their understanding (or lack of knowledge) of autism. Several caregivers in this research believed that there were genetic contributors that caused autism as established and supported in Western and

mainstream medical research (Folstein & Rosen-Sheidley, 2001; Howe, Brand, & Talkowski, 2016) others assumed that the cause of autism was environmental including the vaccination for Measles, Mumps, and Rubella, similarly to the understanding of some families in the research conducted by (Gerber & Offit, 2009). Some caregivers were uncertain on autism etiology and believed it might be both genetic and environmental as highlighted by (Amaral, 2017).

Given Grenada's unique socio-cultural environment and African heritage, some caregivers' conception of autism were understood in the context of Grenadian folklore and cultural traditions. For instance, the belief that cutting a child's hair too early, infidelity and/or adultery may have contributed to an autism diagnosis. Further, some caregivers relied on other supernatural notions such as the practice of Voodoo or Obeah (witchcraft) as justification for autism symptomology and/or diagnosis. These views on correlating autism etiology to paranormal influences  are similar to those held  by some across continental Africa that link the cause of autism to witchcraft, evil spirits and curses (Gona, et al., 2015; Bakare, et al., 2009; Bakare, et al., 2009; Bello-Mojeed & Bakare, 2013; Bello-Mojeed, Bakare, & Munir, 2014) and Voodoo in Jamaica (Mann, 2013).

Some of the participants, the mothers, in particular, felt most responsible for the child's autism symptomology. These feelings are also similar to findings in Taiwan (Shyu, Tsai & Tsai, 2010) and South Korea (Kang-Yi, Grinker, & Mandell, 2012), which also suggest that caregivers, mothers, in particular, felt responsible for a child's symptom development. An overview of the caregivers' narratives in Grenada supports both natural and preternatural contributions to autism aetiology. Indeed, autism is a broad and complex issue making it incredibly challenging to discuss in infinite and conclusive terms (Amaral, 2017). However, cultural factors can certainly influence an individual, family and community's belief about disability in general and on autism in particular as outlined above.

**RQ3. How did caregivers learn to become well-informed to support Autistic individuals and/or persons that may be Autistic in Grenada?**

As I have mentioned elsewhere in this thesis, the experience of being a caregiver for an autistic person and/or someone that may be autistic can be complicated and fraught with obstacles (Hoefman, et al., 2014). The caregiving role has been explored extensively across the geriatric, developmental, health and disability literature (Grossman & Webb, 2016). However, on caring for an individual with special needs, autism included, the research has almost exclusively focused on caregiver burnout. While there is an acknowledgment that caregivers are a necessary form of support for some autistic persons, the current research on how to support caregivers in low and middle-income countries is sparse, for example, Kenya (Cloete & Obaigwa, 2019) and Qatar (Kheir, et al., 2012).

This being said, there has yet to be a study that looks at the support network or how caregivers learn to become competent and efficient carers for an autistic person that may require support within the Caribbean region in general and across Grenada in particular. Consequently, the findings from this research must be geographically contextualized as support and service systems vary between cultural groups, communities and indeed across the developed and developing countries. For instance, what might be useful and meaningful for caregivers within North American context may not be relevant for caregivers on a small island nation like Grenada with constrained financial capital and limited human resource. Accordingly, caregivers must access support and services that are responsive, worthwhile and meaningful in addressing their needs in supporting themselves and the autistic person (Murray et al., 2011). With this in mind, I explored how participants in the caregiving role learn to become more competent and confident in providing safe and useful support to the autistic person.

While there are no established formal system for educating caregivers in Grenada, the data usefully identified some supportive structures about

assisting and coaching the caregiver's wellbeing and in assisting the autistic person. Four main themes were identified within the data. These were:

1. Children's Health Organization for Relief and Educational Services (CHORES) Grenada (CHORES)
2. Support from the school system and educators
3. Online Engagement/ Learning
4. Intuitive support

## Children's Health Organization for Relief and Educational Services (CHORES)

Consideration of the benefit of CHORES was identified from the outset by many caregivers as important. CHORES is a not-for-profit, health organization based in Florida, United States. Healthcare professionals from the organization (pediatricians, anesthesiologists, occupational and speech therapists; prosthetic specialists, behavioural therapist and educators) visit Grenada to donate their time and expertise to assist individuals and families with health and disability challenges (Gov, 2015). The positive impact of CHORES on Grenadian caregivers is a demonstration of the importance of effective collaboration or partnership as essential and best care practice in autism support and education. In this case, the collaboration between the Ministry of Health, Ministry of Education, the business sector, CHORES and caregivers working within shared goals on supporting individuals and families most in need.

Dunn, Constable, Martins, & Cammuso, (2016) state that collaboration is centred on "improving communication between the medical and educational communities in order to improve care for children and support families" (p 4). Moreover, Hanson & Lynch, (2004) suggest that collaboration with caregivers, acknowledges and respects the strengths and unique background of each family and considers their capabilities when making care decision. Evidently, the partnership between the Grenadian caregivers, the CHORES experts, the

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private sector and the multisector collaboration between the government ministries considered the importance of communication and the unique needs of each family unit. The data, as presented in chapter 3, emphasized an enriched experience for both caregivers and the person on the spectrum who was involved with the CHORES program.

Caregivers also spoke about the benefit of having the support of an inter-professional team to teach them support strategies as well as to support the person on the spectrum *(see chapter 4.3.1)*. For instance, caregivers spoke about receiving psychoeducation (the process of providing education on a mental health condition) on autism and nutritional guidelines for the person on the spectrum (Mukhtar, Hastjarjo, Kumara, &amp; Adiyanti, 2018). Some caregivers spoke about learning valuable parenting skills and engagement activities from the occupational and behavioural therapist while others spoke about learning diverse ways to communicate with their child with the support of speech and language therapist. Likewise, caregivers highlighted the benefit of learning essential self-care strategies for dealing with the challenges of caring for someone with special needs.

Summers (2016) suggests that an interprofessional/ multidisciplinary approach is most beneficial in improving the services and support for the individuals living with special needs and their families. "Inter-professional collaboration aims to establish a partnership between health care providers and the client (including family members or other caregivers) which is a participatory and interactive relationship and provides a coordinated approach to care" (p 18). The CHORES inter-professional support was not only beneficial to the Grenadian caregivers knowledge attainment and skill development, but it may have also benefitted the autistic person relatively to the increased access to multiple health care professionals and the provision of coordinated service and support. The expectation is that this kind of exposure to inter-professional and multidisciplinary support will contribute to awareness, improved health outcome and better quality of life for the person living with autism and their caregivers.

**Educators & the school system**

Educators within the school system were noted as instrumental in connecting Grenadian caregivers to the CHORES program and provided other learning and skills development opportunities to these caregivers. Garbacz, Mcintyre, & Santiago, (2016) suggest that for caregivers of individuals living with autism that the involvement and relationship with educators are critical in supporting positive student outcomes. Indeed, educators can help parents and caregivers understand their child's disability and challenges by engaging in open and respectful communication. It is also suggested that knowledge exchange between educators and caregivers about disability and support strategies are most useful when it is shared using several mediums, including handouts, websites, reading materials and parent-teacher meetings (Garbacz, Mcintyre, & Santiago, 2016). The caregivers in this research also spoke about the meaningful interaction with the educators across several mediums, parent-teacher meeting in particular on informing them on their child's unique needs and strengths and in empowering them as parents and caregivers in providing meaningful support.

The caregivers were also candid about challenges with engaging educators. The literature highlights that a positive caregiver and school relationship benefits caregivers and students (Mereoiu, Abercrombie, & Murray, 2016). Therefore, it is essential that the school system and educators continue to communicate and interact with caregivers in open and honest conversation as it will affect the quality and extent of caregiver's involvement in their child's learning and education. Additionally, and as suggested from the findings when caregivers engage with educators/ school system, they may acquire ideas from the school and educators on how to continue to support their children, more importantly, these caregivers may benefit by becoming much more confident on the importance and value of their involvement within the school system and in their children's education. Although there are benefits in the educator/caregiver relationship I was unable to explicitly assess the

receptiveness of educators to caregivers input and intuition within the education system.

**Online Engagement/ Learning**

Before a confirmed autism diagnosis and for those persons that may be autistic, many caregivers are faced with uncertainties and often have questions around explaining the individual's behaviour and trying to decide what they should do next in terms of treatment and support (Interactive Autism Network, 2019). Several caregivers in Grenada reported utilizing online resources and training to begin educating themselves about autism and the supports their child may need. This finding is comparable to research conducted in the United States that suggests that parents/ caregivers' first point of contact for information gathering and treatment decisions is often through the internet (Interactive Autism Network, 2008). The caregivers that consulted online for more focused training and education on autism disclosed that it would have been more effective had the training been more culturally relevant. This reflection by the caregivers is supported by Heitner & Jennings, (2016) who suggest that "…a lack of understanding about culturally responsive issues and practices to meet the needs and expectations of online students and learners can lead to miscommunication, mistrust, poor guidance, frustration, attrition, and delayed program completion" (p.55). It seems that there might be an opportunity to incorporate more diverse and culturally responsive content into online learning environments for adult learners, and if achieved successfully, it may contribute to more equitable and inclusive spaces for all learners including those from geographical and culturally diverse backgrounds.

**Intuitive support**

Despite having some access to health professionals, support systems and contact with online learning spaces, some carers, mothers, in particular, reported their reliance on intuition to parent and support to their autistic child. For this research, intuition is viewed as a nonconscious process in making

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decisions and consists of an internal feeling of knowing without a rationale for the knowledge as described by (Sadler-Smith & Shefy, 2004). For these caregivers, learning to listen to that "inner voice" "gut feeling" and/or their own childhood experiences throughout the mother -child relationship was necessary and took precedence over any ideas or recommendations by health specialist concerning their child's development and needs. The current literature on parenting and intuition is limited, and there is no evidence that a collective maternal instinct exists (Plevinski, 2016). However, there might be value in considering that unconscious sense in parenting that something is wrong (or right) and an acknowledgement that as caregivers trust their intuition, they are somehow connected to their authentic selves and the needs of their child. Kamrath, (2013) suggested that "One of the greatest gifts we can give our children is teaching them to listen to their intuition by learning to listen to our own" (p.31).

Caring for an autistic person can present a unique set of challenges, and so caregivers are often encouraged to find support networks to help develop their knowledge, judgment and skill as caregivers. There is an assumption that these competencies are necessary to be in this caregiving position. Indeed, the participants in the study identified acquiring caregiving competencies and learning through their involvement with health and education professionals, online engagement and learning to trust their intuition to guide and care for their child living with and/or suspected of autism.

**RQ4. What further support did caregivers identify they need?**

**RQ5. What recommendations did caregivers supporting Autistic individuals and/or persons that may be Autistic suggest is needed to improve the quality of life for themselves and the autistic person?**

The last two overarching research questions focused on barriers to caregiving support and what caregivers felt was needed to improve their own caregiving experience and the lived realities for the autistic person.

**Barriers to caregiving support**

This study identified several barriers to caregiving support that are consistent with those mentioned in other caregiving studies globally. As I have mentioned in chapter 2, most of the research on Autism spectrum disorders have been conducted in developed and English speaking countries (Canada, United States, etc.) where there is extensive professional support and services (Samadi & Mcconkey, 2011). There is minimal information on the prevalence and identification of people living with ASD in non-Western, less affluent and developing countries where access to support and services for those living with autism and other disabilities are limited (Samadi & Mcconkey, 2011; Samadi & Mcconkey, 2012). Indeed, this has been the experience of the caregivers in this research who spoke overwhelmingly about the restricted access to professional support such as medical doctors, psychologist and educators in supporting the person living with ASD on the island. This finding is similar to studies by (Samadi & Mcconkey, 2011) and (Mann, 2013) who investigated the experiences of caregivers supporting individuals living with ASD in the Islamic Republic of Iran and the realities of mothers caring for a child with autism in Jamaica respectively. Samadi & Mcconkey (2011) and Mann (2013) both highlighted the numerous challenges, including access to trained professionals that families faced who are caring for persons living with autism in low-income and middle-income countries.

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Another barrier caregivers spoke about is the delay in getting an autism diagnosis which may be a contributing factor to the relatively low prevalence rate of  on autism he island and across the Caribbean region in general, where there are individuals who may be autistic who may be undiagnosed or misdiagnosed. Missigman (2017) suggests that the delay in diagnosis may be connected to a few issues including a lack of autism specialists, cultural skepticism and a genuine unawareness about the disorder.  For several of the caregivers in this research, a confirmed autism diagnosis was noted as crucial as it provided clarification and an incentive for caregivers to learn more about autism and supports.

The importance of receiving an early diagnosis and early intervention for autism is well-established in the literature (Matson, Nebel-Schwalm, & Matson, 2007; Osborne & Reed, 2008; Boyd, Odom, Humphreys, & Sam, 2010). However, what is sparse is research that recognizes the need for cultural sensitivity and cultural responsiveness in the diagnostic and treatment process when supporting individuals, families, and caregivers from diverse ethno racial and cultural backgrounds (Soto, et al., 2014), for example, the consideration of language differences in the screening and assessment procedure. So, while access to professional support might be limited and can have an impact on an ASD diagnosis, it would be imperative especially in low-income countries like Grenada that indigenous approaches be considered that will ascertain the particular needs of the individual and caregivers while being respectful of their cultures. Certainly, within the context of Grenada with limited access to professional support, caregivers rather than professionals are likely to provide much of the specialist support to autistic individuals.

For many people with disabilities, autism included, assistance and support are prerequisites for participating fully in society and to achieving a decent quality of life (Krieger, et al., 2018). When the support and structures are lacking or inadequate, it can create situations where people with disability become overly dependent on family members or caregivers. Eventually, this co-dependent relationship can prevent both the person living with the disability and their

caregiver from becoming socially included and economically active. Several participants in this study shared with this researcher the challenges they encounter when assisting the autistic person in their activities of daily living, education, employment and community participation. They noted that the barriers have further isolated them from meaningful inclusion within the wider Grenadian community. For instance, some participants spoke about the inaccessibility to reliable road network and lack of access to reliable and affordable transportation that has negatively impacted on their social and economic wellbeing. Similar findings have been reported among caregivers in Singapore (Ng, 2009), Jamaica (Mann,2013), Iran (Samadi & Mcconkey, 2011; Samadi & Mcconkey, 2012), Ethiopia (Abdullahi, 2017) and the United States (Whittier, Scharlach, & Santo, 2005).

Whittier et.al, (2005) argued that in suburban and rural areas that lack of available transportation is a significant barrier to accessing supports and services for autism. As noted in the previous chapter, the participants from the rural parts of the island, in particular, distinguished this as a significant barrier to full inclusion and community participation.

Caregivers in this research also spoke about the financial impact of supporting autistic people, and it is well documented that supporting someone with autism presents many emotional, social and economic challenges to caregivers (Bilgin & Kucuk 2010; Gona 2016). Other studies have also shown that because of the unique needs of autistic people, it can often affect quality of life for the entire family unit due to the enormous cost of service provision, for example, accessing private speech therapy, caregiver income loss, medical expenses and other out of pocket expenses (Roddy & O'Neill, 2018). In turn, the caregivers in Grenada may be faced with additional and different challenges such as poverty, unemployment, limited resources, stigma and general beliefs around the causes of disability. To this end, caregivers may continue to experience unique barriers that may impede on their ability to provide meaningful and quality care to the autistic person.

**Improve caregiving experience**

One of the primary contributions the researcher hoped to make in addition to contributing to the literature was also to encourage future conversation amongst Grenadians around the care practices and support for caregivers and autistic people. The expectation was that these discussions would promote greater awareness and education on autism that may be beneficial to those on the spectrum, their families and society at large. Through this researcher's conversation with the fifteen participants, several needs were identified as valuable to become more competent and confident as caregivers, in supporting autistic people and in continuing the autism discourse on the island. Many caregivers spoke about the need for more financial assistance, access to more professional and social supports to help with their skill development and expert information on autism, given the barriers mentioned above. These findings in this study are consistent with and comparable to studies from higher-income countries which noted that caregivers expressed the need for social support, financial support and professional services about autism as relevant (Heiman, 2002; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012).

Further, studies from lower-income countries, for instance, Brazil (Gomes, Lima, Bueno, Araújo, & Souza, 2015) and Tanzania (Ambikile & Outwater, 2012) specified that caregivers also articulated the need for professional, educational, financial and social support as necessary in their various caregiving role. The unmet needs of the caregivers in this study and comparison to the literature appears to be similar, and this is likely because of behavioural presentation or needs of autistic people regardless of race, culture or geographical location. What is different is access or the service provision for autistic people in high-income countries vs low and middle-income countries. In this case, many of the individuals living with mental health and developmental disorders in Grenada, autism in this regard, do not get any or minimal service provision; many remain undiagnosed, and there is limited specialist support and inadequate special schooling. Furthermore, interventions are limited and by extension unavailable in the rural parts of the island. These findings in Grenada

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are very similar to the experiences of caregivers in Ethiopia, supporting autistic individuals as reported by (Tilahun, et al., 2017).

This study suggests that public awareness of autism in Grenada needs improvement. Caregivers disclosed the need for a process that will support and enable others (government, businesses and organizations) to be much more involved in supporting the views, experiences and concerns of caregivers and the autistic person. I mentioned before there is a critical gap in ASD research in low income and developing countries. This knowledge deficit about ASD may have contributed to the misconceptions and social stigma that surrounds an autism diagnosis across the Grenadian society. The research findings suggest that in order to effectively address these issues and to minimize the social stigma that may be associated with autism, there must be careful investigation and collaboration with the various community stakeholders such as businesses and NGO's. Such information would be critical for planning adequate and responsive autism education, awareness, policy guidelines and advocacy that would benefit autistic individual, their caregivers, the wider Grenadian community as well as the various education and health support and services.

Indeed, an informed community can make a difference in the lived experiences of those most marginalized in our society and the caregivers in this research, despite the many challenges, had specific goals, hopes and dreams for the autistic person. These included hopes that the autistic person will find meaningful employment and that they will be able to live relatively independent and "normal" lives. These sentiments shared by these research participants echo the experience of caregivers within the literature, in particular, those supporting transitional age individuals into post-secondary employment, education and independent living (Anderson, Sosnowy, Kuo, & Shattuck, 2018). As mentioned in the previous chapter, although the participants had different perspectives on what hopes and dream meant in the context of the autistic individual. In essence, the participants hopes and dreams were that the autistic person would be able to live in a society where they feel included allowing for a better relationship between the autistic and those that are

neurotypical. The hopes and dreams that autistic people and their caregivers will be connected to meaning supports, services and people that would be able to guide and support them through issues that may arise. These caregivers hoped that those that are not affected personally by autism would become more aware and willing to advocate for inclusion and visibility for those that living with various kinds of disability.

**Caregiver Challengers and Policy Considerations**

In this thesis and within the Grenadian cultural context a caregiver was described as anyone (parent, relatives and friends) who provided primary care or who was most responsible for an autistic person. The evidence from this research suggested that these caregivers provided the vast majority of support to autistic individuals, many of whom lack the resources needed to support these complex caregiving tasks. For instance, the caregivers in Grenada had limited access to appropriate information and training and other supportive services and are shouldering personal and economic difficulties in supporting the autistic person. (See figure 4 for a summary of the research finding).

Given the key challenges as discussed above, a comprehensive policy framework is necessary to sustain caregivers so that they can provide useful support to autistic individuals while addressing barriers and their potential negative impacts on caregivers and the autistic person. Currently, there is no public policy in Grenada that recognizes and responds to the needs of caregivers. Further, a review of the existing landscape of caregiving policies is absent across the English-speaking Caribbean. There is an urgent need in Grenada and by extension the Caribbean region, to establish caregiving policy frameworks as well the need to review and amend existing policy options to build on and to improve the social, economic, health and education outcomes for caregivers and autistic people.

In Grenada, for example, the Education Act (2012) is a legislative framework providing the legal basis for interpretation and development of education

policies within the island. Arguably, this legislation needs to be amended to address the specific needs of caregivers and autistic people. The Education Act (2012) makes provision for special education programs for students of compulsory school age (5 to16 years). While the Ministry of Education has established a "Special Education Unit" to promote inclusive education for students living with disabilities, the current system remains inadequate in supporting the education and unique challenges of students living with various kinds of disabilities (physical, developmental and mental health).

The current legislative and policy framework also does not explicitly include or make provisions for voices of caregivers, notwithstanding, the responsibilities and the critical role they place in their child's development. Moreover, there is a need for a pedagogical shift in policy and practice towards inclusive social justice practices for caregivers, autistic people and other marginalized groups within the Grenadian society. This shift in policy and practice must include consultation from several stakeholders including caregivers, relatives, teachers, healthcare professionals, religious members and other interested community groups.

The perspectives shared in this research indicate that caregivers in Grenada require more support and resources to ensure that autistic people have access to improve on their life possibilities, including the right to quality education, appropriate support and services and safe and inclusive society in general. Governmental engagement and collaboration particularly with the Ministry of Social Development, Housing and Community Empowerment, the Ministry of Education, Human Resources, Religious Affairs and Information and the Ministry of Health, is fundamental and can potentially have enormous positive social change implication for autistic people, caregivers and the wider Grenadian society. This may include the development of training and education to better equip caregivers to provide meaningful and respectful support to the autistic person. This may contribute to improvement in caregiver outcomes, such as a decrease in negative thoughts and feelings in the caregiving role (caregiver burnout). Recognizing the roles and responsibilities of caregivers

from a policy level may highlight other gaps within the system and may empower caregivers, autistic people and other interested parties to take action in holding the government responsible for social, health and economic equity and for the sustainable improvement in the quality of life for all Grenadians.

## Reflections, Limitations and Future Research Directions

### Researcher's reflections

In chapter 3 of this thesis, I claimed that this research was developed within the framework of narrative ethnography. I suggested that the narrative ethnography provides the framework for storytelling that considers the mechanism of communication, situational circumstances, the purpose and reason for telling a story, how the story is told as well as the resources that are available (or lack thereof) in shaping the production of these stories (Gubrium & Holstein, 2009). I highlighted that this approach moves beyond traditional analysis/ thematic analysis that focuses almost exclusively and is restricted to text in the storytelling process, and does not intentionally consider the social organization and interactional dynamics of storytelling. Although the research was short term (4 weeks), it leads itself to the principles of ethnography that explores group (often a culture) and the activity with language and lived realities (Gubrium & Holstein, 2012). In this research, I attempted to understand, organize, produce and share the experiences of caregivers supporting autistic individuals in Grenada. Emphasis was placed on the influence of the social-cultural and economic context of the Grenadian society in the [re]storytelling process.

On reflection, a longer-term narrative ethnographic investigation into the experiences of these caregivers may have been more prudent and may have provided much more context on the caregivers' experiences and by extension on the lived realities of autistic people on the island. In consideration of the foregoing, I maintain that narrative reality of this research on the following underpinnings; that our experiences as humans are always organized into narratives, that these narratives cannot be understood simply as text or abstract structures separated from their cultural context and that narratives are

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multivoiced (Moen, 2006).  In other words, the personal stories I heard from these caregivers are indeed shaped by their knowledge, experiences and values and collectively these stories were shaped by "cultural, historical and institutional settings in which they occur" (Moen, 2006).

As stated in chapter 3, this narrative approach is situated within the qualitative research methods grounded within constructionism and interpretivist philosophical positions (Soini, Kronqvist, & Huber, 2011). One of the main features of this approach is the collaboration/ partnership between the researcher and the participant and as I have mentioned before, I attempted to make sense of and interpret the perception, knowledge and experience of caregivers supporting autistic individuals or persons that may be autistic within the Grenadian context. What appeared to be an important factor in the dialogic nature of the relationship between these caregivers and myself was creating a space where we both felt comfortable. However, in considering the stories that I chose to share in chapter 4, it appears that I may have been more willing to highlight the voices and experiences of the male participants.  In reviewing the raw data, it was also evident that the interviews with the male participants were longer in duration and possibly provided more content for analysis, but why is that? One possible explanation may be connected to this researcher's level of comfortability, I accept that within the research process that it may have been easier for the male storytellers and myself to reach joint intersubjective within the narrative environment, this may be connected to our male privilege or possibly to my unconscious bias.

It is claimed that a non-judgmental attitude and a sense of equality between participants are fundamentally important within narrative inquiry (Moen, 2006). This is especially true for women who have traditionally experienced exclusion in research and whose voices are often absent (Burnier, 2003). Considering this history and the reality that women are more likely, to be the caregivers of autistic people in Grenada, it would be critical that their voices are more intentionally included in research and empowered to tell their stories.

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A final note on reflection, earlier in the thesis I suggested that as a clinical social worker that my practice is embedded within an anti-oppressive framework. Anti-oppression focuses on ending social and economic oppression and invites practitioners to be self-reflective while they critically examine and negotiate the power differentials that are present with structures across sociocultural and political spaces (Baines, 2020). I further suggested that my understanding of autism was mostly understood from a socially constructed and neurodiversity perspective. Reflecting on my Ph.D. journey, from the proposal to the collection of the data and analysis and within the dissemination of that information, I am certain that I need to engage in much more intentional self-reflective work that will demonstrate a commitment to social justice and social change. This is especially true as I am now more aware of the influence of the biomedical model of disability on my intellectual and practice; for instance, some of the language used in this thesis like treatment and intervention for many individuals can be oppressive and exclusionary, this is even more concerning within cultural or minority communities whose understanding or perspectives may be different. Musing on the stories from these caregivers, and reflecting on my "clinical" practice within a hospital system. I am determined to demonstrate and advocate that the issues caregivers and autistic people face are rooted in the inequalities and oppression that are social, political and economic and that working against those kinds of injustices would create opportunities for agency, autonomy and self-advocating for autistic people and caregivers alike.

**Limitation and Future Research Directions**

There were several important findings in the present study, which revealed critical implications for autism research, education and practice in Grenada. These findings and implications should be considered within study limitations, which point to important future research directions. A strength of this study is that the participants were reflective of the urban and rural spaces across Grenada an accounted for a range of experiences. The sample for this study was relatively small (15 caregivers), and although it fostered in-depth information, these findings may not generalize to a large and diverse sample of

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caregivers on the Tri Island (Grenada, Carriacou and Petite Martinique). The research was only conducted on the mainland Grenada. Future research should aim to include more samples of caregivers of autistic individuals across the Tri Island nation to further explore and detail these caregiving experiences. Another limitation is that the study included caregivers supporting autistic individuals with an official diagnosis as well as those without an official diagnosis. The experiences and perspectives of caregivers supporting an autistic individual with a confirmed diagnosis may be different from those that are undiagnosed.

Additionally, caregivers in the study were supporting individuals ranging from age 8 to 33 who may be autistic. The perceptions of caregivers who are caring for an autistic adult may be different from those supporting younger children; further research should explore these separately. This researcher did not explore the educational level, economic realities and other social determinants of the participants. A comprehensive inquiry on these social locations/markers may provide useful content on the caregiver perception and conceptualization of autism. Next, caregiver views were the basis for exploration in the study. However, future research should include multi-source exploration, such as direct observations of the autistic person at home and/or school to provide a more comprehensive, balance and meaningful reflection on what it might mean to be autistic in Grenada. Furthermore, exploring the perspective of professionals (teachers, health professionals), wider family networks and the community may also be useful to provide additional context and evidence of the need for further training and development for caregivers.

**Implications**

This study is the first in Grenada among caregivers of autistic individuals and in addition to contributing empirical knowledge to the literature; there are implications for research policy and practice. First, given the unique challenges that caregivers experience as noted throughout the thesis, more indigenous research would be helpful in order to establish prevalence rate, policy and

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procedural guidelines as well as advancing a global understanding of autism especially for those in low and middle-income countries. Second, given the lack of knowledge on autism and the stigma that is pervasive within Grenada's society, there is a need to develop interventions/ approaches that addresses stigma, improve public awareness as well as improve access to appropriate services for autistic people and their caregivers. Third, the research findings suggested that caregivers held both supernatural and medical opinion on an ASD etiology. It would then be necessary that professional supports, especially those that are coming from the high-income countries be respectful and empathetic to the needs of Grenadian caregivers and where it is possible to collaborate with faith communities in assisting caregivers and autistic individuals. Fourth, while remaining sensitive to Grenadian culture and folklore, it would be important that psychoeducation is provided to caregivers, the autistic person and the Grenadian society on the causes of autism as well as helpful and useful intervention that will promote an enhanced quality of life for autistic person and the caregiver. Fifth, Grenada is a collectivist society which means community and group values are considered more important when compared to an individual value. It is, therefore, critical that a community-based approach is utilized to provide psychosocial support for caregivers and autistic individual and since the island is low income with minimal resources perhaps non-autism specialist (teachers, nurses, family members, peers) can be trained to deliver the psychosocial and psychoeducation support.  Sixth, local organizations like the Autistic Foundation of Grenada should continue to highlight the challenges that are present for autistic people and their caregivers while continuing to advocate for increased autism awareness, support and services. Finally, the partnerships between the various Government ministries, NGO's and international organizations such as CHORES should become more formalized and established. Significant consideration should be given towards caregiver education, knowledge exchange and support since caregivers it seems are most responsible for the person on the spectrum on the island.

**Conclusion**

Caregiver involvement holds unique importance for autistic individuals. This present exploratory research provides an examination on the experience of caregivers in Grenada supporting autistic persons including their perception and conceptualization of autism, their process of knowledge attainment, and the barriers to support and services they experience as well as their suggestions towards the improvement in supports and services. Limitations notwithstanding, the research findings indicated a set of diverse experiences for caregivers, including several etiology on autism that are not mutually exclusive, both challenging and rewarding experiences in their various caregiving roles, training and support for caregivers, some barriers to support and some useful suggestion for improvement. The goal of this study was not to evaluate or generalize results, but to understand in-depth the experiences of caregivers supporting autistic individuals within the Grenadian social context. This research has implication for policy development directed towards reducing stigma and exclusion of autistic people and their caregiver; increasing awareness about the cause of autism and addressing the needs of caregivers of autistic persons, including how to best support their learning and knowledge attainment. Further, there is a need for more culturally sensitive and responsive psychosocial and psychoeducational support to increase awareness about autism as well as enhance the access to appropriate support services for caregivers.

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# Appendix A- Recruitment/ Schematic representation

## Appendix A

**Phase 1**

Purposive Sampling using pre-existing connections (research flyer + participant information shared)

**4 participants recruited**

**Phase 2**

Snowballing (initial participants asked for help identifying other people with similar interest in research)

**6 potential participants**

**Phase 3**

Social Media outreach (LinkedIn, Facebook, Twitter, Online Newspaper)

Research flyer shared

**5 potential participants recruited**

**Phase 4**

Researcher engaged in data collection

**15 participants**

1st contact via telephone

- review participant eligibility
- review research objective & purpose
- address concerns
- set a deadline

2nd contact via telephone

- confirm interview & details
- review research participant information in details
- address any concerns

3rd contact: in person interview

-review research details (data collection methods, compensation)
- address any concerns

Data collection & Analysis

**Phase 5: in person contact (feedback)**

- Findings presented to research participants
- Participants asked to provide feedback
- 2nd compensation
- Necessary changes made before submission
- Submission

**Figure 3:** Schematic representation of the recruitment, data collection and analysis process

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# Lancaster University

**An Exploratory study of parents, family & friends (caregivers') perceptions and experiences supporting individuals living with or suspected of Autism Spectrum Disorder in Grenada.**

*Help is needed from primary caregivers of person living with or suspected of Autism Spectrum Disorder (ASD) who live in Grenada*

I want to hear about your experience as a primary caregiver!

**What is the study about?**

**We are exploring the following:**

- **What it is like for you supporting individuals suspected and/or living with an ASD in Grenada**
- **What your opinion is on current resources and supports**
- **Your suggestion on what needs to change to improve the quality of life for yourself and the person living with and/or suspected of ASD in Grenada**

**What will I have to do?**

**You will have to sign the consent form indicating that you have read and understood the explanation provided to you about this research. You will also agree to be available for the 1 ½ to 2 hours for an interview and observation.**

**Who to contact if you are interested?**

**If you are interested in participating in this study, please contact Leo. Edwards at 647-295-6235 or email me at l.edwards1@lancaster.ac.uk**

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

**Thank you for considering your participation in this project**

# Appendix C-Participant Information Sheet

**Lancaster University**

**Participant information sheet**

**Project Title: An Exploratory study of caregivers' perceptions and experiences supporting individuals living with or suspected of Autism Spectrum Disorder in Grenada.**

I would like to invite you to take part in a research study which is part of my PhD studies in the Department of Educational Research at Lancaster University. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

**What is the study about?**

There has been extensive research and a wealth of data generated that recognized the understanding and experiences of persons on the Autism spectrum in the last decade however in the Caribbean region there is still a significant lack of research and data on disability, autism in particular. The purpose of this study is to fill this research gap by exploring the experiences, perception and understanding of parents, relatives, friends (caregivers) in Grenada who supports individuals living with and/ or suspected of Autism. The questions guiding this study include:

*1. What are the lived experiences of caregivers supporting individuals suspected and/or living with an ASD in Grenada?*

*2. How do caregivers supporting persons suspected and/or living with an ASD conceptualise these experiences?*

*3. What further support do caregivers identify they need?*

*4. What advice would caregivers supporting persons suspected and/or living with an ASD suggest is needed to improve the quality of life for themselves and the person with ASD?*

**Why have I been invited?**

I am looking for caregivers (parents, relatives, and friends) who are providing primary care or who are responsible for a person(s) living with or suspected of Autism Spectrum Disorder (ASD). If you do, I would like to hear from you and would be very grateful if you would agree to take part in this study.

**Do I have to take part?**

Your participation in this research is voluntary. However, you will receive a small compensation in two parts ($60 EC at interview/observation and $ 40 EC at feedback) for your time and participation. You may withdraw and discontinue participation in this research within 4 weeks without any consequence.

**What will I be asked to do if I take part?**

Again, your involvement in this project is voluntary. You may find the discussions/interviews interesting and thought-provoking, however, if you feel uncomfortable in any way during the interview session, you have the right to decline to answer any question or to end the interview. If you change your mind, you are free to withdraw your participation in this study. If you want to withdraw, please let me know, and I will extract any ideas or information you contributed to the study and destroy them. However, it is difficult and often impossible to take out information from one specific participant when this has already been anonymised or pooled together with other people's information. Even so, you can withdraw up to 3 to 4 weeks after taking part in the study

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to avoid inclusion of your information. This one-time interview and observation will last approximately 1 ½ to 2 hours and is expected to take place at a location you are most comfortable that is safe, confidential and mutually agreed to. The interview will be audio recorded and observational notes will also be written during the interview process. The interview and notes will be transcribed and coded for analysis. You will not be identified by name in any report using the information obtained from the interview and observation, pseudonyms will be used and to the best of my ability your confidentiality as a participant will remain secure by removing all your identifying information. Additionally, you will have access to my initial notes and transcripts to ensure accuracy in capturing and reflecting your information from the interview and observation. No one else will have access to this initial data. Afterwards, the fully anonymised data will be offered to Lancaster University's institutional data repository (PURE) and will be made available to genuine research for re-use (secondary analysis). Because the study involves the collection and analysis of data, it may be some months before its findings can be officially written up. However, I will meet with you again for a 30 to 45 minutes session on the results that emerged from this research and for your feedback before submission for the partial fulfilment of the requirements for the degree Doctor of Philosophy in Education and Social Justice. The results may also be submitted for publications or presentations by this researcher.

**What are the possible benefits from taking part?**
**The potential benefits of participating in this research study include:**

1. Contribute to the understanding of the experiences caregivers face supporting persons on the spectrum/ or suspected in the context of Grenada.

2. Increasing the awareness and understanding of ASD in the context of Grenada.

3. Informing and advocating for system changes that are more responsive and inclusive for people living with Autism.

4. In addition to informing the Grenadian public on ASD, the research can potentially encourage further discussion on the experiences of persons living with autism within the wider Caribbean region.

**Risks or Discomfort**

This research is considered to be minimal risk. This means that the risk associated with this study are the same as what you face each day. There are no known additional risk to those who take part in this study.

**What will I have to do?**

You will have to sign the consent form indicating that you have read and understood the explanation provided to you about this research. You will also agree to be available for the 1 ½ to 2 hours for an interview and observation.

I appreciate that you may wish to gain further information about the project before deciding to be involved, so please feel free to phone me at 1-647-295-6235 or email me at l.edwards1@lancaster.ac.uk

If you have any concerns about the project or my conduct as a researcher please contact:

Dr. Sue Cranmer

Department: Educational Research
Tel: +44 (0)1524 592870
s.cranmer@lancaster.ac.uk

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

**Appendix D-Recruitment Sample**



http://www.nowgrenada.com/2018/03/study-on-primary-caregivers-of-persons-living-with-or-suspected-of-autism-spectrum-disorder/

## CONSENT FORM

Lancaster
University

**Project Title: An Exploratory study of caregivers' perceptions and experiences supporting individuals living with or suspected of Autism Spectrum Disorder in Grenada.**

Name of Researchers: Leo D. Edwards
Email: l.edwards1@lancaster.ac.uk
**Please tick each box**

| | |
|---|---|
| 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily | ☐ |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time during my participation in this study and within 4 weeks after I took part in the study, without giving any reason. If I withdraw within 4 weeks of taking part in the study my data will be removed. | ☐ |
| 3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included and I will not be identifiable. Fully anonymised data will be offered to Lancaster University's institutional data repository (PURE) and will be made available to genuine research for re-use (secondary analysis). | ☐ |
| 4. I understand that my name will not appear in any reports, articles or presentation without my consent. | ☐ |
| 5. I understand that any interviews will be audio-recorded and transcribed and that data including the notes made in observations will be protected on encrypted devices and kept secure. | ☐ |
| 6. I understand that data will be kept according to University guidelines for a minimum of 5 years after the end of the study. | ☐ |
| 7. I agree to take part in the above study. | ☐ |

_____    _____    _____
Name of Participant              Date                       Signature

**I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.**

**Signature of Researcher /person taking the consent_____ Date _____** Day/month/year

**One copy of this form will be given to the participant and the original kept in the files of the researcher**

**Interview Protocol**

**Time of Interview:**
**Date:**
**Place:**
**Interview:**

**Semi-Structured Interview Guide**

1. When did you first hear the word autism as a way of describing (NAME) behaviours? How old was (NAME) at the time? What was your reaction when you first heard the term autism? What do you know about autism? How do you describe it?

2. Did (NAME) receive an official diagnosis? If yes, did you feel supported during the process? If not, what were the barriers to an ASD diagnosis? *(Probe for details)*

3. Tell me how you have been affected by caring for (NAME) living with/ suspected of ASD?
    Impact on family
    Impact on relationships
    Impact on work life/ education
    Impact on self
    Impact on finances

*(Probe for positive and negative if necessary)*

4. Can you describe your current *(informal)* support system? In what way do they provide support to you *(emotional, financial, etc.)*

5. Can you describe your current *(formal)* support system? Are there any supports specific to caregivers in Grenada? If yes, what is your experience with them? If not, do you feel that specific caregiver support wound be beneficial? And what should these supports look like?

6. Are you receiving any formal support/ services for (NAME)? If yes, can you describe your experience accessing them? If not, do you feel that support/ services would be beneficial? And what should these supports look like?

7. Can you describe what day to day life is like caring for (NAME)? *(Probe for caregiving roles, stressors and coping, seeking help, inclusion opportunities, self-care & enriching experience)*

8. Given your experience caring for (NAME), what you believe needs to change (if anything) so that you are better able to support (NAME) and yourself as a caregiver?

**Appendix G- Ethical Approval**

# Ethics approval (REC reference number FL17066 -please quote this in all correspondence about this project)

FASS and LUMS Research Ethics

Reply all|

Mon 2017-12-18, 9:52 AM

Edwards, Leo;

Cranmer, Sue

Inbox

Dear Leonard

Thank you for submitting your ethics application and additional information for *The caregiver experience supporting people with Autism in the context of Grenada.* The information you provided has been reviewed by member(s) of the Faculty of Arts and Social Sciences and Lancaster Management School Research Ethics Committee and I can confirm that approval has been granted for this project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress) to the Research Ethics Officer;

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please do not hesitate to contact me if you require further information about this.

Kind regards

# Debbie

**Debbie Knight**

Secretary, FASS-LUMS Research Ethics Committee fass.lumsethics@lancaster.ac.uk

Phone (01524) 592605| D22 FASS Building, Lancaster University, LA1 4YT | Web: http://www.lancaster.ac.uk/arts-and-social-sciences/research/ethics-guidance-and-ethics-review-process/ & http://www.lancaster.ac.uk/lums/research/ethics/

www.lancaster.ac.uk/50

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