

## **Chapter 1: Introduction**

Parents who care for children with a disability often result in stressful experiences. The families, in some cases become overwhelmed to the point that it affects the home and leads the family into serious crisis. This chapter will explore the lives of three (3) Jamaican families who have children diagnosed with autism. The chapter will also highlight the background to the study the rationale and research questions that guided the study. This chapter will conclude with the significant of the study and definition of important terms.

According to an online article entitled Effects of Autism on the Individual and their Family (2017) ‘parents with children who have a disability may experience more stress than parents of naturally developing children.’ The article further stated individuals with autism and their families are sometimes faced with a myriad of problems such as ‘loneliness, lack of friends, emptiness, few social activities, and little support are among the most common problems’ that they encounter. Some individuals on the autism spectrum (ASD) are also faced with challenges, including feeling accepted. Some of the challenges experienced by children with autism include the frustration of not being able to express how they feel, to having daily crippling anxiety and tantrum because they find it difficult to make sense of their environment. ‘While other individuals with autism spectrum disorder (ASD) and their families cope well with the additional challenges that autism brings, for many others the impact can be devastating.’

The article further stated that ‘children with autism commonly develop stress-reducing behaviours that can make them appear strange or unruly and they are judged by others for behaving ‘oddly’. In addition, the article stated that autism can ‘impact the family in a negative way,’ so that, the parents shun taking their children out to public spaces rather than having to deal with the reactions from people who are unaware to their situation. ‘This may not only cause

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children with autism but also their family to become confined to their home and isolated, which has a great effect on their social and emotional wellbeing.’

Spain et al., 2017, vol. 5 in the journal article Family therapy for autism spectrum disorders, opined that autism spectrum disorders (ASDs) can severely affect the family’s relationship with the child, ‘augment stress and frustration, and contribute to behaviours that can be described as challenging.’ Additionally, Spain et al stated that family of children diagnosed with autism ‘can experience high rates of caregiver stress and burden, and poor parental efficacy.’ Autism Spectrum Disorder (ASD) can cause children to miss out on valuable social, educational, leisure and life experiences that others their age take for granted. In the article Effects of Autism on the Individual and their Family (2017) opined that ‘their confidence and self-esteem deteriorate as a result and many develop depression and other mental health problems.’ ‘Teenagers are especially vulnerable, often being bullied by ‘superficial friends’ or excluded from mainstream school’ (Effects of Autism on the Individual and their Family, 2017). In addition, the article underlines that adolescent’s transition into adulthood can be just as dishearten as the ‘majority does not have the social and communication skills needed to live independently or get a job.’ Often the teenagers who transition into adulthood are left at home and eventually they wander the streets through most of their adult lives. ‘Many find that they are misunderstood and some tragically break the law and commit crimes, often related to their lack of social understanding’ (Effects of Autism on the Individual and their Family, 2017).

When parents first receive the news from a ‘doctor or a teacher that their child is on the autistic spectrum, there is an inevitable period of grieving as they process the news’ (The Economic Impact of Autism on Families, May 2012). Parents must accept the fact that their children will be faced with serious challenges and ‘may miss out on the milestone events, for

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example: a home run on the Little League game, a driver's license, the prom that other parents proudly post on their Facebook page, Instagram page or just take pictures to treasure the special moment' (The Economic Impact of Autism on Families, May 2012). Additionally, the article opined that time helps most parents to heal get over the shame of having a child who is diagnosed autism. The devastating news of having a child with autism is sometimes pushed aside by parental love and pride. 'The parent will accept that the child will have his/her own achievements and will reach different milestones, which they will treasure as much as the traditional ones' (The Economic Impact of Autism on Families, May 2012). Conversely, once parents get over the grieving stage, they have to tolerate a lifetime of caring for their children holistically because they will never be fully equipped to take care of themselves. 'Therapy and caring for a child with autism can be very expensive but if the child is to succeed he/she must receive these treatments. In addition, the article further stated that parents will challenge insurance companies and school authorities to offset medical expenses. Unfortunately many times parents are unsuccessful, and are left with little financial resources and face rejects from hostile school authorities and communities who accuse the family of 'stealing their children's money.' When families must address all these issues, they can become drained both emotionally and financially.

Having a child diagnosed with autism forces the family to find ways to make the child as comfortable as possible and this can be very time consuming. The family will try to find therapists and school to help the child function in society as much as possible. The disorder can become so time consuming that one family may have to stop working and stay home to ensure that all the child's needs are adequately met. According to Economic Impact of Autism on Families (2012), one of the many impacts of autism on families is that 'working on their

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children's behalf becomes a full-time job.' In addition, the article stated that 'one parent, often the mother, either stops working or works fewer hours, in order to manage the child's education needs and also their therapy.' She must take her child long distances to access the required services. In addition, she must navigate bureaucracy of the health care system. In order to get the therapy that their children need she must meet frequently with teachers and school authorities (The Economic Impact of Autism on Families, 2012).

In the article, *The Economic Impact of Autism on Families (2012)*, Ricardo Dolmetsch, an associate professor of neurobiology at Stanford University, said his son's autism diagnosis had changed both his personal and professional life. This work was made more difficult; according to Dolmetsch caring for a child with a disability is a full-time job. Although his wife, 'neurobiologist Asha Nigh, supported his research, such as through managing projects and writing grant proposals, she has put her own scientific career on hold in order to care for their son and his brother, 7 year old brother. In his opinion, Dolmetsch said, his wife has earned an honorary doctorate in getting insurance coverage for stuff.'

In the article, *The Economic Impact of Autism on Families (2012)* the writer cites an example of where the Dolmetsch family was faced with financial challenges due to the addition health expenses. Dolmetsch reported that the only thing that worked for his child was behavioural treatments, and described the cost as being 'brutal,' and 'horrifyingly' expensive. (The Economic Impact of Autism on Families (2012))

## **Background**

Parents who have children with a developmental disorder such as autism face many challenges on a daily basis. Some of these challenges include; educational, social, financial, physical, impact on families.

Spain et al., 2017, vol. 5 in the journal article Family therapy for autism spectrum disorders, opined that autism spectrum disorders (ASDs) can be ‘characterized by impairments in communication and reciprocal social interaction.’

According to the article Exploring stigma: medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder (2009), ‘the autism spectrum describes a range of developmental disorders most commonly diagnosed in early childhood which influence the social and cognitive abilities of those diagnosed.’ The article further stated ‘that children, who after diagnosis, are constructed as occupying a position ‘on the spectrum,’ finds it difficult interacting with others and also finds it difficult to give eye contact. Children diagnosed with autism often time have their speech delayed or find it difficult to express themselves verbally. They may also display ‘antisocial behaviours in the form of withdrawal, aggression, or self-stimulation, sometimes as a reaction to stress or changes in routine.’ For parents, these behaviours can lead to ‘humiliation, social exclusion, and isolation; this can be proven to be true in the Jamaican context.’ In addition, the article went on to say that parents of children diagnosed with an autism spectrum disorder (ASD) must manage a ‘spoiled’ social identity due to the stigmatizing nature of their child’s diagnosis.’

According to the article Effects of Autism on the Individual and their Family (2017), parents can become isolated, depressed, and emotionally and physically exhausted’ from taking care their children born with autism and struggling to get support from stakeholders. The parents

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sometimes feel ‘judged by society, guilty that their child is missing out and frustrated at not knowing how best to help them.’ Additionally, the article further stated that for many families, at least one parent cannot work due to constant supervision, care and responsibilities and this puts an enormous economic burden on them. Often, persons with autism have ‘disturbed sleep patterns and they need constant supervision which may be physically exhausting’ (Effects of Autism on the Individual and their Family (2017)). As they grow up, parents may experience behavioural challenges especially when the child throws a tantrum. Many Jamaican parents with children diagnosed with autism believe that they will be the primary caregiver for life and are often very worried about what will happen to their children when they die or get old. All too often, the stresses of living with someone diagnosed with autism may cause separation within the family and this adds to the feeling of isolation and despair.

The researcher is an educator at a primary school in St. Andrew. She has over 10 years of teaching experience. During her tenure, she has encountered parents with autistic children. These parents often times suffer in silence not knowing where to get financial assistance, accessing therapy and to find support groups to help them cope with the stresses of having a child with autism.

### **Rationale**

The impact of autism on families should be of high priority to all stakeholders. The issue of Jamaican families no struggling to cope with their children’s disability not only affects the immediate family but also the schools and the children. In an online article, Edwards (2011) cited that High Commissioner Hallihan likened autism to that of a “riddle wrapped in a puzzle,” which is a ‘tremendously hard one for families and individuals that are touched by this condition’ (Edwards 2011). As a result, it is imperative that the families seek the proper

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interventions to help their children deal with a myriad of issues that autism comes with. Parents with autistic children agonize to know how to ‘communicate (socially and cognitively) with their children and sometimes prefer to keep them at home rather than face stigmatization from the public’ (Edwards 2011).

This research, therefore, seeks to find out the impact of autism on families, emotionally, financially, and socially. The researcher found it imperative to explore this phenomena because she wanted to find out what level of support is given to these families and their children, by the government and other stakeholders to help to alleviate some of the stresses that come with a child that is autistic, for example financial support, resources, programmes and support groups. It is imperative that parents of children born with autism must meet the needs of their children, as well as meet the needs of their family. In essence, are families given the necessary tools to help their child cope with autism?

### **Problem**

Many factors affect families with autistic children which include; isolation, depression, financial stresses, emotional, mental and physical exhaustion from caring for their autistic children. Families are often times misrepresented by the society and they then feel a sense of guilty because their children are missing out on things that children their age are meaningfully engaged in. They become frustrated because they are unsure of how best to help their children. For many families, one parent is unable to work because a child with autism needs constant attention this sometimes can put financial strains on the family. Many families struggle with these issues of caring for their child born with autism, how well the family is able to cope leads to the success or failure of the child. In order to mitigate the stresses some families undergo with autistic children, the impact of autism on families need to be address.

### **Purpose of the Study**

The purpose of this study is to investigate the impact of having a child with autism on the family.

### **Research Questions**

- What are the emotional factors that impact families with a child diagnosed with autism on families?
- What are the financial factors that impact families with a child diagnosed with autism?
- What are the supportive systems offered by the state to support families who have autistic children?

### **Significance of Study**

By conducting this research, the researcher has found out that not many studies were conducted locally, hence, the researcher believes that this study is significant as the data will help teachers, principals, parents, government bodies and all stakeholders to have better understanding of the impact autism has on families in Jamaica. The findings of the study will also be of great importance to all other stakeholders, as they try to find ways to motivate and support parents in providing an environment for their children born with autism that will help them to be empowered to be their best. In addition, this study will be beneficial to future researchers who intend to specialize in related studies to the impact of autism on the family.

- **Principals**

Principals should provide an environment for students' born with autism that will enable them to reach their full potential. Educators must keep in mind the Ministry of Education mantra vision 2030 "Every child can learn...every child must learn" when they are planning programmes for autistic children. It is imperative that principals are trained in Special Education and understand

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the basics of autism spectrum disorders. They should equip the schools with the necessary tools that will help teachers, so that they will be able to help their students to develop holistically.

With this in mind, this study will help principals to prepare workshops and seminars to assist teachers to garner strategies that will be used to help autistic students in the classroom.

- **Teachers**

Teachers must first be trained in Special Education. This special training will help them to de-escalate a situation in their classroom safely and effectively. With principals equipping their teachers with the necessary tools this will allow them to ensure the safest learning environment for children on the autism spectrum. With this in mind, this study will be helpful to teachers because they will be armed with information that can help them to understand and deal with students who are autistic and also understand the myriad of challenges parents deal with on a daily basis.

- **Parents**

Parents are the first source of information about their child born autism. It is therefore, imperative that the school and the parents build a trustworthy relationship throughout the children's tenure. Therefore, this study will assist parents to be relentless when seeking help for themselves and their children diagnosed with autism. It will also help them to understand that their children need them to be their caregivers who must be involved in their lives in every aspect. This direct involvement in their children's lives will help them develop holistically.

- **Stakeholders**

The Ministry of Education could use these findings to create seminars and workshops to highlight the impact of autism on families. Work closer with families and children by providing greater support to these families. This study will also aid them in establishing better programmes

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and policies geared towards the academic and social development of the children diagnosed with autism. In addition, the findings of this study can help the Ministry of Education educate the wider society on being more tolerant with families and their children who are diagnosed with autism. The ministry can educate expecting mothers about early detection and encourage the families to seek help. They can use the findings of this study to help guide them in preparing special education units at all public institutions. This will better assist to alleviate the financial stresses of parents who are unable to pay private institutions to help their children who are diagnosed with autism.

- **Researcher**

With the wealth of knowledge garnered while conducting this study, the researcher will use the knowledge in her classroom to better understand and to be more tolerant with children who diagnosed with autism or any other special needs child. In addition, the findings from this research will be used to develop strategies that can be used in the academic and social development of the children that she comes in contact with. The findings from this research will also help her to be more equipped to guide parents to relevant institutions that can help them and their children diagnosed with autism.

The data will be analyzed and results from this will allow the researcher to reach a conclusion about her study, make recommendations that will be of tremendous value to policy makers, the relevant stakeholders, and families. The results will also help parents to understand the important role they play in their children's holistic development.

## **Definition of Terms**

### **ASD**

Autism spectrum disorder (The Autism Answer Book 2007)

Autism Spectrum Disorders (ASDs), Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, “a spectrum,” of symptoms, skills, and levels of disability.

People with ASD often have these characteristics:

- Ongoing social problems that include difficulty communicating and interacting with others
- Repetitive behaviors as well as limited interests or activities
- Symptoms that typically are recognized in the first two years of life
- Symptoms that hurt the individual’s ability to function socially, at school or work, or other areas of life (National Institute of Mental Health, 2016).

### **Autism**

The word derived from the Greek word autos, or “self” as in autonomous. It has been used to describe individuals who appear to be self-contained or who exist in their own little world, an inner realm seemingly set apart from others. From a physiological perspective, autism is a common neurological anomaly that may preclude the body from properly receiving signals transmitted by the brain, resulting in misfires and disconnects. Thus, people with autism may be unable to speak (or speak reliably), to move as they would wish, or carry themselves with grace and complete agility (The Autism Answer Book, 2007).

**Autism**

Is ‘a neurodevelopmental disorder characterized by impairment in emotional expression and recognition, difficulty with social relationships, delayed and/or abnormal language and communication, and preoccupation with repetitive, stereotyped behaviours or interests’ (Slaughter, Virginia, Ph.D., Magill’s Medical Guide (Online Edition), January, 2017).

**PATH**

‘The Programme of Advancement Through Health and Education (PATH) is a conditional cash transfer (CCT) programme funded by the Government of Jamaica and the World Bank and is aimed at delivering benefits by way of cash grants to the neediest and vulnerable in the society.’

**Shadow**

A Shadow is defined as the act of sending a student with a disability into a general education program accompanied by an aide. In other words, a therapist/aide who is trained in the basic principles of applied behavior analysis. A shadow will accompany the student to the inclusive setting and be a support to the student in that environment. The shadow will assist the student with the skills that he or she already has and help them gain new ones as well.

## Chapter 2: Literature Review

In this chapter the researcher found it imperative to explore literature from different parts of the world; this is due to the fact that there is little literature and research available on autism and its impact on families in Jamaica. The researcher was also faced with challenges when she tried to garner statistical data from the Ministry of Health. She believes that this added information would have aided her literature review to be more content rich.

This chapter will begin by reviewing the literature found on the three research questions;

1. What are the emotional factors that impact families with a child diagnosed with autism?
2. What are the financial factors that impact factors that impact families with a child diagnosed with autism?
3. What are the support systems offered by the government to help families who have autistic children?

The chapter is concluded with the theoretical framework that is used to support the literature found on all three research questions.

Emotional impact on families with a child diagnosed with autism

Bessette, McAlpine, Garwick, and Wieling (2016) opined in an online journal that ‘families experienced autism as a mysterious and complex condition.’ These families are faced with serious ‘communication challenges, stress, and isolation’. The article further stated families with children diagnosed with autism sometimes observe their children harming themselves and harming others. In addition, the article stated children diagnosed with autism have major communication shortfalls which results in ‘isolation between the family and child.’

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Raising a child with autism may cause families to feel overwhelmed, alone and even a feel a sense of rejection by society. According to Miller-Wilson (n.d.) ‘autism brings with it a lot of emotional ups and downs for the family, which starts prior to the diagnosis and continues indefinitely.’ The moment they begin to suspect that their child is not developing in a ‘neuro-typical way’, families of children diagnosed with autism will begin to ‘face challenges that set them apart from other families’. Parents can become emotionally vulnerable before and after hearing their child’s diagnosis. Additionally, Miller-Wilson stated that ‘there’s the stress of navigating complicated therapy schedules, following through on treatment at home, juggling family commitments with job responsibilities, and many other issues’ (Miller-Wilson, n.d.).

The article *The Autism Spectrum Disorder Grief Cycle* (2012), highlighted ‘families, especially the mother, experience a grief cycle which includes; shock and disbelief, denial, anger or rage, confusion and powerlessness, guilt, depression, shame or embarrassment, fear and panic, bargaining, hope, isolation, and acceptance.’

Halterman and Guillermo (2007) in the article *Psychological functioning and coping among mothers of children with autism: A population-based study* volume 119 stated, mothers of children diagnosed with autism often assessed their ‘mental health as fair or poor;’ compared with the general population, their stress level was much higher.’ Their poor mental state will continue even after their child receives speech and behavioural therapy. ‘Often times these parents feel a sense of guilt due to resentment, anger at themselves, doctors and spouse.’ Conversely, they also feel a sense relief because there’s a name for their child’s disorder and they are better able to handle the challenges that come with autism.

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Vacco (2010) in an online article opines autism and its impact does not only affect poor families, but its impact affects families ‘across ethnic, social and economic lines.’ The stresses that autism causes the family can be psychologically devastating.

Vacco cited in the article that ‘Jordan, a pharmaceutical executive, is wealthy by any measurement.’ Wealth however, did not make her any more invulnerable to having a mental breakdown that could possibly be caused by years of caring for her child diagnosed with autism. The article further stated that Jordan, ‘a divorced mother of child with autism, was arrested for the murder of her 8-year-old boy, Jude.’ In addition, the article further stated the mother gave her child a ‘lethal combination of prescription drugs.’ Additionally, the article opined ‘Jude’s father mentioned that his son was a “good boy” but seeing him suffer was heartrending, he would thump his head on the floor and scream.

Children, born with autism spectrum disorder (ASD), encounter stigmas in society due to their constant outbursts and tantrums. According to Sarris (2015), parents of children with autism have not had a moment in public when their children are not making outbursts and throwing tantrums. As a result parents of children with autism are often times treated with disdain from the public. The parents will be treated with hostile words such as, “Control your child.” Maybe the ‘annoyed individuals assume their child lacks discipline; or maybe he recognizes the disability but blames you for subjecting him to such behaviour.’

Meirsschaut, M., Warreyn, P., & Roeyers, H. (2011) wrote in journal article that mothers with children diagnosed with autism experience more stress in comparison to those mothers with children who develop normally. The study revealed that mothers with a children on the ‘autism spectrum disorder (ASD) showed signs of stress, depression, guilt or low parental self-efficacy beliefs.’

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Families coping with children diagnosed with autism come with many stress related situations that can create stronger family units or break these families. It takes a lot of work and excellent support groups to help these families create a holistic environment for their children.

Wilson (2011) in a Jamaica Observer online article stated that ‘emotional support is crucial for parents of children diagnosed with autism.’ Wilson cited in the article that it is with this premise that mother of one, ‘Kathy Chang and another parent started the Jamaica Autism Support Association (JASA) over four years ago. The group started with about five parents of autistic children who would meet up to share some of their challenges in raising their children. The group now consists of over 100 parents, caregivers, and professionals who meet every last Saturday at the YMCA to encourage and support each other.’ Additionally, Wilson (2011) further stated in her article that Chang and the co-founder are two mothers who realized that having somebody to talk to about our challenges was helpful. She stated that ‘they formed the group to help other parents who were going through what they were going through. In addition, Wilson highlighted that ‘Chang’s nine-year-old son Kyle, was diagnosed with autism at two years old.’ Chang found it ‘refreshing’ to sit and have honest conversations with other individuals about autism and its impact on her family; she was also comforted by the fact that these persons understood what she was going through. Wilson (2011) further alluded to the fact that ‘at the time of Chang’s son diagnosis, there was not much awareness of disorder in Jamaica; hence there were very few people who could relate to her struggles.’ Because of the lack of study on autism in Jamaica Chang had to seek ‘therapy for her son in Florida where she eventually met the five women, who became the founding members of JASA.’

The article reported that the group became a 'registered non-government organization in 2007 and attracts women from all socio-economic levels who want to learn how to be better parents to their child with autism.' According to Wilson, JASA become an important organization to parents, especially 'single mothers whose children don't receive any form of help or therapy at all.' These parents are welcomed to the organization where they are able to liaison with other parents. They are taught valuable skills and children are given speech therapy that will help to make their lives and the life of their child diagnosed with autism less stressful, these skills include, how to 'potty train their child, and other things they can do to stimulate the child to talk.' Wilson wrote in the article that 'professionals who attend the monthly meeting usually dispense information and offer training through workshops that are organized by the group.'

Wilson (2011) opined in the article, that one of the 'major challenges faced' by parents of children with autism is how they will finance the treatments that their children need to make their lives more meaningful. Children with autism also demand a lot of attention. She stated 'the therapy is not cheap and parents must pay for their children schooling which is already expensive and then you have to 'pay for the shadow (support person) and whatever extras he requires.' The article further explained some of the things 'Chang budgets for in caring for their son who attends school with a shadow.'

Wilson cited in the article that Chang alluded to the fact that some people say that autism likened to that of a 'death sentence.' When Chang was given the news by her physician that her son was autistic, she left the doctor's office without speaking and drove home numbed. This is so because parents does not 'what is out there, what is the future for their child, what can their child

do, is he just going to be unable to help himself and be totally dependent on you for the rest of his life?’

In closing, Wilson cited in the article that Chang is ‘happy that there is more discussion and awareness about autism which affects a number of Jamaican children. On April 2, members of the JASA joined with other stakeholders to release 1000 balloons at Emancipation Park in Kingston to commemorate World Autism Awareness Day. April is World Autism Awareness Month.’

Collinder (2008) cited in an article in the Jamaica Gleaner that Maia Chung-Smith was forced to find ways to help meet the needs of her son who was diagnosed with autism. As result of the family’s pain and not knowing how to help their son, ‘Chung-Smith created Jamaica's first Autism Foundation in collaboration with a coalition of professional volunteers.’ The aim of the foundation is to help those families who are affected by the ‘physiological condition.’ In addition the article stated that ‘autism is defined as a brain disorder that affects development and can affect a person's ability to communicate, relate to others, and interact with his or her surroundings.’ Collinder also cited Chung-Smith in the article saying that the individuals who affected by autism are likely to be treated as a ‘mad person’, ‘persecuted and ostracized.’ The article further stated that Chung-Smith has gotten a myriad of calls from parents with children who are autistic on the verge of ‘committing suicide because they frustrated and depressed.’ Parents with children diagnosed with autism must be bold to face the many challenges that come with the disorder, they must also be willing to stop at nothing to get the help they need so that they better able to assist their children.

Financial factors that impact families with a child diagnosed with autism.

Autism can have a negative impact on families due to necessary therapies needed for the child to function. Parents must find money to cover the cost of all other treatments and doctors' visits that their child must have in order to lead a success life. Paltrow (2015) opined that families with children who are diagnosed with autism often 'face a huge financial burden.' 'Expenses for autism treatment and therapies are not covered by most private health insurers, and they are quite expensive.' The parents must stand the cost for 'medications and office visits often and this often lead to a great financial burden. 'Families with child a diagnosed with autism suffered an average loss of 14 percent in their entire family income.' It is imperative that both parents are working because caring for their child is very expensive, but eventually one parent will stop working because their child needs full-time care and attention. 'So, the family has to bear the increased expenses, in spite of having a lowered household income. Full-time employment is important for many parents for providing health insurance, and so, losing a full-time job may dramatically affect the family's financial condition.'

Meral (2012) opined in the online journal entitled A study on social support perception of a parents who have children with autism, 'poverty' and the lack of income impacts the family with a child diagnosed with autism greatly. Additionally, Meral cited in the article Dalaker (1999) 'expressed that poverty can be having less total household income, of family and family members.' Parents who do not have an income or have a low income will find it difficult to support their child's therapy and educational needs. The article further stated that there is a relationship between 'income and inadequacies.'

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The online article *The Financial Impact of an Autism Diagnosis* (2017) highlighted the fact that parents of children with autism have ‘additional expenditures that can turn a middle-income family into a low-income family in a matter of months. Unfortunately, poverty amongst families with an autistic child is growing in the United States at a rapid rate, and there are not enough government-funded programs available to assist them.’ Additionally, the article pointed to the fact that it is difficult to put a cost to raising a child with autism. The article further stated that according to the ‘Centers for Disease Control (2016), one out of every 68 children is diagnosed with a form of autism. The severe financial strain associated with the diagnosis does not help the fact that the families with autistic children generally earn 28 percent less than families with non-autistic children.’ The costs of caring for a child with autism include, ‘but are not limited to; the loss of one parent’s income, special schooling, special equipment, special activities and lacking health coverage.’

The economy climate can be very rough on families around the world, but there are some families who are affected more than others and this is due to their socio-economic background. According to the online article *Educating and Advocating for Low-Income Families with Children with Autism on How to Obtain Health Insurance Benefits for Autism Related Interventions* (2017) stated in the ‘United States to-date, even with the recent shift to include those in the Healthy Families program in the new mandate, low-income families with children with autism still face many health-care related access issues, including lack of autism specialists working with low-income populations, long waiting lists, language and cultural barriers, transportation issues, and other financial barriers.’

The online article, *The Financial Impact of an Autism Diagnosis* (2017) stated that children with autism require continuous ‘care and stimulation.’ Although caring for the child

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diagnosed with autism can be done by a caregiver, many parents want to protect and care for their child by themselves and as a result they ‘choose to quit their job and stay home to care for their child. In a nuclear family, one parent must shoulder the burden of earning enough income to support the family and the extensive cost of care.’

Autistic children need to be in an institution that caters to their needs. This will help the children develop some necessary skills needed to stimulate growth. In addition, the article *The Financial Impact of an Autism Diagnosis (2017)* highlighted the fact that ‘children with autism often cannot attend the same classes or schools as non-autistic children.’ This is because they require a teaching and learning environment that suits their learning needs. ‘Specialty schools, tutors, and teachers can cost families several hundred dollars per month or thousands per year.’

In the online article *Financial Impact of an Autism Diagnosis (2017)* stated that children with autism also need to be engaged in ‘extra-curricular activities these activities can help with their social development.’ It has been shown that activities geared towards children with autism help them learn to function in a normal environment. These activities include ‘special camps, swimming lessons, and social events, but these activities can be expensive.’ Parents can spend hundreds of dollars every year sending their children to these special events that are imperative for the ‘social development of their child’ (*Financial Impact of an Autism Diagnosis (2017)*).

McArdle (2012) in an online article opines that ‘caring for a child with a disability is a full-time job.’ In her studies, she found a family that consisted of an associate professor Dolmetch of neurobiology at Stanford University and his wife Asha who is a neurobiologist. According to the article, Dolmetsch stated the “finances of autism are brutal”. He further emphasized “The amount of continuous care these kids need is a lot; the only thing that works at

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all are behavioral treatments, which, depending on the state and one's health plan, may not be covered by insurance.” he says. “They're very intensive and they're horrifyingly expensive.”

McArdle (2012) found that ‘mothers of children with autism earned, on average, less than \$21,000 a year.’ In addition, McArdle stated that was ‘56 percent less than mothers whose children had no health limitations and 35 percent less than mothers whose children had other health limitations.’

A child diagnosed with autism needs several services to assist in their care and this can often time be financially stressful for the parents. According to Hartman (2012), a child may need evaluations, home programs, and various therapies which can be expensive.’ Hartman further stated that after the ‘child turns eighteen and the parent wants to continue having custody of that child, court and a nominal guardianship fee is required.’ Hartman emphasized that one parent has to give up his/her job to help take care of the child;’ this can become financial burden on the family and because it now leaves one parent to support the entire family.

White (2013) in an online article interviewed a mother, Davidson, who has an autism son. Davidson explained that her son was ‘diagnosed with autism a lifelong brain disorder that affects the way a person communicates and relates to people around them.’ Her son ‘Christopher Clarke was seven years old when he was diagnosed as autistic at the psychiatric ward at Cornwall Regional Hospital.’ She said that at age nine, her son was attending the ‘School of Hope,’ but had she had to stop him last year June at age 15 because of ‘financial difficulties.’ “Mi can't manage to send him because it cost me to send him to school and at that time mi have this one (two-year-old son) too.”

White cited in the article that Davidson said that her son’s father played an active role in their son’s life up to ‘age nine when he moved out of the house’. She said that it was a

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financially and emotionally it was much easier when he was there, 'as they would take turns working.' Davidson related that now she is unable to work because of her son's inability to function on his own and because 'everywhere I go I have to take him with me.' He is unable to stay by himself and I have nowhere to leave him, and 'I cannot leave him alone.' It's difficult to even get a 'part-time' job. The reported that a lady 'created a position for me once as an office helper and I did a little filing too, but she didn't really want anybody she just created the position for me.' But since that time she is unable to work. According to White, Davidson has 'resorted to begging just to ensure that he (her son) eats before she takes him on the street in the morning, feeds him sometimes on the street and when he gets home.' Davidson reported that there are times when he gets up at night and throws his tantrums because 'he wants something to eat.' "Sometime mi all have to send him out a door at night until him calm down," she said. "But sometimes mi only can afford to feed him one time for the day." Her begging on the street sometimes 'earns her \$500, while contributions from friends could push it up to \$3,000 per day.'

Support systems offered by the government to help families who have autistic children.

Raising children with autism in the 21st century can be very challenging and as a result, families need as much support as they can get. According to the online article Programs and services for Children with Autism (2016), stated that the 'Ontario Government has put in place an autism intervention programme where the family doctor or psychologist may refer the family to a regional autism service provider for autism intervention services. These services are funded by the Ministry of Children and Youth Services. The Autism Intervention Program includes advice, information, materials, consultation and training for families to get their child ready for Intensive Behavioural Intervention.'

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The online article Programs and services for Children with Autism (2016) reported that the 'Intensive Behavioural Intervention programme is a structured approach that breaks down the barriers that isolate children with autism from the world around them based on the principles of Applied Behaviour Analysis. Intensive Behavioural Intervention uses structured methods to motivate 'development and change behaviour.' The programme goals are separately designed to fit each child and this is 'based on a thorough assessment of the child's unique strengths and needs.' The aim of the programme is to develop the skills each child needs for 'greater independence;' Intensive Behavioural Intervention 'professionals work with children with autism - either individually or in small groups. Parents are critical to the success of Intensive Behavioural Intervention.'

According to the article the program has a 'parent-training component' so that parents can be equipped to better assist their children to reach their goals. 'Children and young adults who are getting Intensive Behavioural Intervention don't stop receiving autism services just because they reach a certain age but is continued throughout the life of the child.'

The International Electronic Journal of Elementary Education, 9(4), 829-836, (2017) published an article entitled, Quality of Educational Support for Children with Autism Spectrum Disorder in Bosnia and Herzegovina Perception of Parents and Professionals, highlighted that, 'children with autism spectrum disorder (ASD) attend regular education schools and special education schools in Bosnia and Herzegovina. Regardless of the setting, it is important to provide early, high quality, programs to children with ASD. High quality educational support must encompass evidence-based programmes for these children.' In addition, the article furthered that 'high-quality, evidence-based supports and services must be a common-place for children with autism in various educational settings.' Parents and caregivers must to be educated

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as ‘co-therapists’ and work in partnership with ‘special education teachers in improving the educational outcomes of children with ASD.’

It is imperative that the government of Jamaica play an active role by helping families with children diagnosed with autism. The government can help to subsidize school, medical expenses and also help with counseling for both families and their children.

The in an online article entitled Ministry of Labour and Social Security (2006) opined that the ‘Early Stimulation Programme is an extension of the Jamaica Council for Persons with Disabilities that provides an assessment and early intervention programme for children with disabilities from birth to six years old.’ Children on the programme are assisted from across the island but most of the attention is placed on the Kingston and St. Andrew areas and also Portmore. In addition, the article stated that the programme offers services such as ‘professional identification and assessment of developmental disabilities in pre-school children, formulate and implement specific intervention programme(s) catering to the individual needs of children with the assistance of parents, provision of home-based teaching in order to minimize the need for institutionalized care and resource center to other agencies serving young children by providing consultations, referrals, intervention programmes and parent training.’ The early stimulation programme does not only serve children diagnosed with autism but also seeks to help children with various disabilities, these include:

1. Multi-disabled, Intellectually challenged, mental retardation, learning disability
2. Impaired-hearing or visual, Lacking in language development
3. Physically challenged, Behavioural problems
4. Cultural familiar retardation, Attention deficit disorder

## 5. Autism, Cerebral Palsy, and Down Syndrome (Ministry of Labour and Social Security (2006)

According to the article parents must have a child that displays ‘delays in development as demonstrated by a suspect score on the Denver Developmental Screening Test (DDST)’ in order to qualify for this programme parents. This involves a series of test that the child must take, these include; ‘A medical, developmental, social and behavioural history is completed using a standard protocol.’

‘The assessment process that the child undergoes includes; Developmental Screening on the Denver II Developmental Screening Test (DDST) and Physical and psychomotor assessment on the Jamaica-Portage Checklist. Evaluations are done in areas of cognition, self-help, language, motor and socialization. The medical examination with screening for neurological impairments, vision and hearing impairments invites parents to the orientation sessions to allow a forum for question/answer and to sensitize them to their role within the Early Stimulation Programme.’

According to an online article found in the Jamaica Observe, written by Wilson (2012) the ‘Maia Chung Autism and Disabilities Foundation (MCADF) is set to discontinue all forms of outreach activities, effective today, citing Government's obvious disregard for those living with the mental disorder.’ The foundation was ‘motivated by the diagnosis of one of her three sons with autism, Chung established the foundation to lobby for children suffering from the developmental disorder, which impairs social interaction. The MCADF has organized various fundraising initiatives geared toward helping to subsidize care, medication, school fees, and even groceries for parents of autistic children.’ In addition, the article stated that with the ‘awareness of autism and its symptoms’ has caused many parents to take their children in to be tested and

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‘diagnosed.’ With the added number of children being diagnosed, ‘special needs schools, she said, are being placed in a position where they have to stretch their meager budget to accommodate parents who cannot afford the high school fees and needed to educate children with autism.’

In addition Wilson (2012) article opined that, there needs to be much more ‘Government intervention at this level.’ Wilson cited in her article that Chung stated that, “because identifying a whole bunch of people who are affected by a situation and not having anywhere for them to go is a waste of time.” Wilson cited that Chung is ‘disappointed that her effort and resources that her group has plunged into her foundation to keep ‘special needs schools functional over the years; two have been closed down while at least one more is on the brink of closure.’ Additionally, the article reported that Chung was disheartened and wonders, what will happen to these children who have nowhere else to go? “When these close and there are dearth already, what do we do then?” she asked, ‘while pointing to a lack of viable solutions and intervention from the Government.’ Wilson highlighted that Chung said she has often ‘lobbied on the behalf of these schools, given their need for Government intervention, but she said her cries; for the most part seem to have fallen on deaf ears. She further stated that the last Government subvention her group received was in 2009 of \$100,000 to assist some students.’

### Theoretical Framework

Woolfolk (2010) opined that Maslow's Hierarchy of needs suggested that humans have a hierarchy of needs ranging from lower-level needs for survival and safety to higher-level needs for intellectual achievement and finally self-actualization. Woolfolk further stated that self-actualization is Maslow's term for self-fulfillment, the realization of person potential.

Maslow's hierarchy of needs is often been represented in a hierarchical pyramid with five levels. The four levels (lower-order needs) are considered physiological needs, while the top level of the pyramid is considered growth needs (Learning Theories, 2014). The levels are as follows (see pyramid below).



- Self-actualization – includes morality, creativity and problem solving
- Esteem – includes confidence, self-esteem, achievement and respect
- Belongingness – includes love, friendship, intimacy and family
- Safety – includes security of environment, employment, resources, health and property
- Physiological – includes air, food, water, sex, sleep and other factors towards homeostasis

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A child diagnosed with autism needs must be met by using Maslow's Hierarchy of needs; where the great emphasis must be placed on the lower-level of needs before there can be improvements that will influence behaviour.

By critical analyzing Maslow's Hierarchy of Needs it would be easier for a middle-class and upper-class family in Jamaica to meet the needs of their child born with autism. This is due to the fact that these families would have greater access to facilities and finances that will help garner well-needed support for their child born with autism. The impact on a family with a child born with autism at the lower class in society can be greater. This is due to the fact that these families would find it harder to give support to their child because they have less financial support or income to support the home. This child is now seen as a burden because the parent(s) is unable to give adequate care for him/her. This theoretical framework show that the more affluent the family is the better able they will be able to cater to their children's needs. If the family is unable to finance the child's speech therapy, behavioural therapy and all the other areas that the child will need to address, then this child will not be able to reach his or her own milestone. And eventually may cause the child to not move or even get worse.

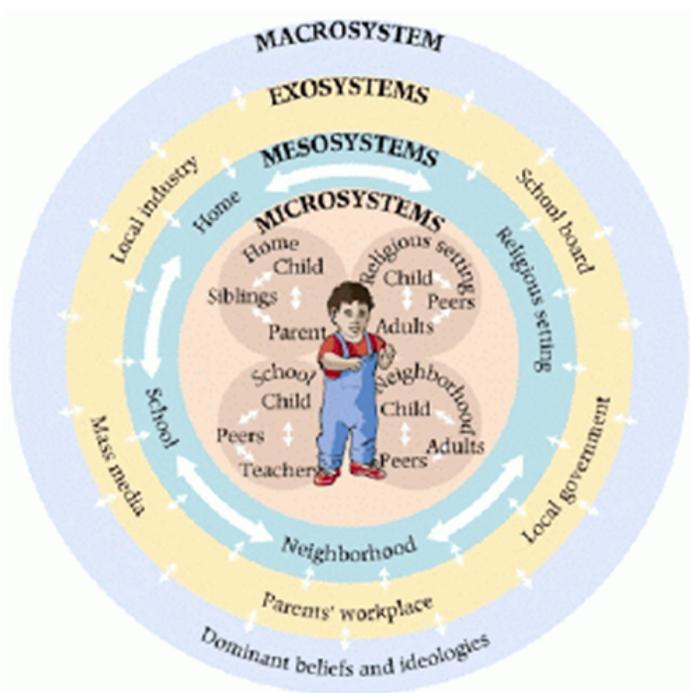
Meral (2012) cited in an online article that 'poverty can be expressed as having a less total household income, of family and family members, than the income level limit determined by related organizations' (Dalaker, 1999). In addition, Meral cited that families that are poor, 'who have a child with developmental disability, are affected from poverty more than poor families with a normal developed child and wealthy families who have child with a development disability.'

The home is the first point of interact and as such parents play an integral part in the lives of their child diagnosed with autism. The parent(s) seek the necessary support that will assist to

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equip their child function and reach their milestones in their time. This can only happen when the parents heal emotionally and come to terms with their child's diagnosis; then they will be able to take on all the challenges that come with diagnosis.

According to Woolfolk (2010) cited that 'Urie Bronfenbrenner (1917-2005) developed a frame to map the many interacting social context that affect social development.' In addition, Woolfolk cited that 'Bronfenbrenner theory recognizes that people bring their biological selves to the developmental process.' In addition, 'the ecological part recognizes the social contexts in which we develop are ecosystem because they are in constant interaction and influences each other.' Bronfenbrenner suggested that 'every person lives, learns and develops within a set of 'nested system' from the immediate family to the neighbourhoods and schools to the community and society.'



Bronfenbrenner's theory impacts this study because his model speaks about each individual being a part of a system and one system having an impact on the other. Therefore, the family is the first nested system, if children diagnosed with autism do not have a strong home

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system they will fail. The second nested system is the school; this is where special emphasis is placed on developing the necessary skills needed for the child to be better able to function in the wider society. Hence, the parent, child, teachers and school administrators all learn from each other. For example; the child was in microsystem which is the home. He then moved to the mesosystem which is the school. In this system the child learn to socialize and adopt new behaviour. The child then moves to the exosystem where he further learns new behaviour within a larger environment. The final stage is the macrosystem where teaching and learning further takes place.

### **Chapter 3: Methodology**

“For autistic individuals to succeed in this world, they need to find their strengths and the people that will help them get to their hopes and dreams. In order to do so, ability to make and keep friends is a must. Amongst those friends, there must be mentors to show them the way. A supportive environment where they can learn from their mistakes is what we as a society needs to create for them.”

~Bill Wong

#### **Participants**

The researcher used participants from different institutions in the St. Andrew area at the primary level and secondary level to assist in her study. The researcher also used purposeful sampling to support study; this is due to the fact that it allowed her to garner richer data. According to Creswell (2012) ‘in purposeful sampling researchers intentionally select individuals and sites to learn or understand the central phenomenon. In addition, Creswell (2012) stated that the standard used in choosing participants and sites is whether they are information rich.’

The purpose of this study is to investigate the impact of autism on families in Jamaica. The participants will be parents both male and female from the different socio-economic background.

#### **Design**

The researcher chose to conduct a qualitative case study research because it was the best method that could help her understand how the participants feel and also to understand the values families place on helping their child diagnose with autism develop holistically. This method also helped the researcher to capture the language the participants used to describe their journey with their children diagnosed autistic.

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‘A qualitative case study methodology provides tools for researchers to study complex phenomena within their contexts. When the approach is applied correctly, it becomes a valuable method for health science research to develop theory, evaluate programs, and develop interventions’ (Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers, 2008).

According to Creswell (2012) ‘a qualitative research is used best to explore a phenomenon in which you do not know the variables and need to explore.’ Merriam and Tisdell (2016) stated that ‘qualitative research is the essential guide to understanding, designing, conducting, and presenting. It reaches beyond the what, where, and when of quantitative analysis to investigate the why and how behind human behaviour and the reasons that govern such behaviour.’

The purpose of this chapter is to inform all stakeholders on the different instruments used in an effort to collect valid data for this study.

### **Instruments**

The researcher used questionnaires and qualitative semi-structured interviews to assist in her data collection (questionnaire see appendix B and semi-structured interview see appendix A).

‘A questionnaire is a form used in a survey design that participants in a study complete and return to the researcher. The participants choose answers to questions and supplies basic personal or demographic information’ (Creswell 2012).

‘An interview is a form on which researcher records answers supplied by the participants in the study. The researcher asks a question from an interview guide listens for answers and observes behaviour, and records responses on a survey’ (Creswell 2012). These methods of data collection were chosen because they provide an efficient way of obtaining information.

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In a semi-structured interview, the researcher sets the outline for the topics covered, but the interviewee's responses determine the way, in which the interview is directed. This is the most commonly used type of interview used in qualitative research. The 'semi-structured interview guide provides a clear set of instructions for interviewers and can provide reliable, comparable qualitative data. Semi-structured interviews are often preceded by observation, informal and unstructured interviewing in order to allow researchers to develop a keen understanding of the topic of interest necessary for developing relevant and meaningful semi-structured questions. The inclusion of open-ended questions and training of interviewers to follow relevant topics that may stray from the interview guide; does however, still provide the opportunity for identifying new ways of seeing and understanding the topic at hand' ( Kluwer 2013).

The researcher used a qualitative approach to carry out purposeful sampling. The data collected was used to make conclusions about the larger population based on information garnered from the sample. The researcher conducted one-on-one interviews with parents and hand out questionnaires within one week.

### **Procedure**

In this study, the researcher interviewed three participants on autism and its impact on families. A semi-structured qualitative interview was conducted and questionnaires were given out in order to collect imperative data. The researcher contacted her participants through email, Whatsapp messages and telephone. The researcher conducted one-on-one interviews with parents and hand out questionnaires within one month. Participants were first contacted by email during the months of March and April to arrange an appropriate meeting time and place. The interviews were conducted in a confidential, convenient place chosen by each participant. The

researcher also emailed the participants an information sheet regarding the content of this research along with the questionnaire and interview.

The researcher asked sixteen questions on the questionnaire and main questions on the semi-structured interview sheet with follow-up questions for further exploration on the topic autism and its impact on families. The interviews took approximately forty-five minutes to one hour. The interviews were audio-recorded by the researcher and participants were informed.

These methods also allowed the researcher to gather past behaviours and opinions including personal facts which are imperative to this study. In addition, the researcher also used member checking to help validate the accuracy of her findings. This check involves taking the findings back to the participants and asking them if the report is accurate. 'Validating findings means that the researcher determines the accuracy or credibility of the findings through strategies such as member checking or triangulation' (Creswell 2012). According to Creswell (2012) participants were asked about many aspects of the study, such as whether the description is complete and realistic, if the themes are accurate to include, and if the interpretations are fair and representative.

### **Data analysis**

The researcher used coding to help process and analyze her data. She also used coding in this study to help categorize the data into a number of categories. 'Coding is the process of segmenting and labeling text to form descriptions and broad themes in the data' (Creswell 2012). 'The objective of the coding process is to make sense out of text data, divide it into text or image segments, label the segments, examine codes for overlap and redundancy, and collapse these codes into a broad theme' (Creswell 2012). In doing this, the researcher was able to identify the similarities and differences between families who are impacted by autism through semi-

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structured interviews. The researcher found it imperative to use description and theme coding after transcribing audio-recorded interviews in order to obtain all important information for this study. According to Creswell (2012) ‘description is a detailed rendering of people, places, or events in a setting in qualitative research.’ In addition, Creswell stated that the ‘use of themes is another way to analyze qualitative data because themes are similar to codes aggregated together to form a major idea in the database.’

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FIGURE 1.1 Key Participant=A1	
Theme and Description in questionnaire on Autism and Impact on families	
Emotional Theme	Quotation from participant 1
Abandonment	<ul style="list-style-type: none"> <li>A1 reported that she did not receive help from a government institution. She tried getting help from the Ministry of Health but they were not proactive at the time when her son was diagnosed with autism</li> <li>She further stated that the M.O.H statistic information was not correct at that time and as a result, she had to do her research. It was because of frustration and trying to get help for her son that she decided to create the organization Jamaica Autism Support Association (JASA) that would support other parents who are faced with great challenges with caring for their child/children, and also it was a coping mechanism for her. She said profoundly that she has never received any support for government agencies.</li> <li>In addition, participant A1 stated that her son's diagnosis and the other medical issues that came with autism put a strain on the family which led to her and her husband's divorce.</li> </ul>
Denial	<ul style="list-style-type: none"> <li>A1 said that she noticed something was wrong at 18 months and she remembered coming across an article on autism years before she had her son. She recalled that her discernment led her back to the autism article she read years before with the various characteristics ASD. She exclaimed "no sah that can't be real! Mi neva hear nobody talking about autism". "Autism can't just choose my family outa so many families". After reading the article and making further observation her son she knew he was autistic. She said she reported her findings to her husband and he replied "mi neva hear bout that condition before". They both keep saying "no, no, no, it can't be", but after 18 months and observing her son's repetitive behaviour and lack of speech then comparing him to her 2 older sons she knew then wholeheartedly that her fears were true.</li> </ul>
Feeling overwhelmed	<ul style="list-style-type: none"> <li>A1 exclaimed "Lawd gosh, in the initial stage it was daunting."</li> </ul>

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FIGURE 1.2	
Theme and Description in questionnaire on Autism and Impact on families	
Financial Theme	Quotation from A1
Salary	<ul style="list-style-type: none"> <li>Earns over \$ 20,000.00 monthly which enhances the quality of her son's life. Salary helps to pay school fees, purchase books, clothing and activities her son is involved in.</li> </ul>
Support system	<ul style="list-style-type: none"> <li>A1 reported that she has not received any support from a government institution. She visited The Ministry of Health (M.O.H) in 2009 and she was given information that was incorrect. The Ministry advised her that there were only 5 children in Jamaica with autism she recognized that there was a lot of disparity and disconnect between the M.O.E and persons who were seeking answers to help their children with autism.</li> <li>She received support from family members she elaborated that her family is tertiary level educated and as a result, it was easier for them to accept her son's disability. She also revealed that she received support from the church family.</li> </ul>

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FIGURE 1.3 Key Participant 2= A2	
Theme and Description in questionnaire on Autism and Impact on families	
Emotional Theme	Quotation from A2
Abandonment	<ul style="list-style-type: none"> <li>A2 reported that in the initial stage of her son's diagnosis someone recommended that she visits Jamaica Autism Support Association (JASA). She said, "Miss, mi neva feel so alone and rejected". She saw them as being some up-town parents all they did was talked about themselves and fundraisers they are involved in. She stated that she did not feel eloquent enough to speak with this group of women she didn't like the group. She felt as though she was below (status) these parents even though all of them have children with autism and so she never went back.</li> </ul> <p>A2 stated that her son's father could not handle the frequent tantrums and additional challenges that autism brings so they eventually broke up.</p> <ul style="list-style-type: none"> <li>A2 said that she did not reject nor was she in denial because she did not know what autism was at that time. She stated that "autism was a new phenomenon for her. Mi di clueless; all I could do was cry, I couldn't stop crying", retorted A2.</li> </ul>
Denial	
Feeling overwhelmed	

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FIGURE 1.4 Key Participant 2=A2	
Theme and Description in questionnaire on Autism and its Impact on families	
Financial Theme	Quotation from A 2
Salary	<ul style="list-style-type: none"> <li>Earns over \$ 20,000.00 monthly which enhances the quality of her son's life. Salary helps to pay school fees, purchase books, clothing and any other activities her son is involved in at school.</li> <li>Participant 2 stated that her son's father gives financial support to their son.</li> </ul>
Support system	<ul style="list-style-type: none"> <li>A 2 stated that she has received support from the school. She stated that noticed that her child was not developing as a typical child would so she took him to Early Stimulations on Hanover Street. Participant 2 reported that a nurse told her that "she did not want to say what she thinks her son diagnosis was but added that her son demonstrated echolalia, because her son only repeated what she said to him". Participant 2 reported that although they gave her advice, she was not sure of what her son's disability was.</li> <li>A 2 said that the Bustamante Children's Hospital also played an integral role in assisting her to understand all the other medical challenges her son has.</li> <li>She was encouraged by a doctor at Bustamante Children's Hospital to take her son to McCam Child Development Center where he could be tested and diagnosed. Participant 2 explained that the individuals at McCam Development Center told her that her son was mildly autistic.</li> <li>She received support from her mother. She stated, "My mother is my tower of strength".</li> <li>A 2 stated that the school that the child presently attends caters to his needs. She emphasized that the school her son attends is not a government institution.</li> <li>She further stated that she received assistance from The Jamaica Council for Persons with Disabilities. She stated that this institution continues to assist her with school fees, uniforms and book grants. She further stated that the only drawback is that this assistance is only given at the beginning of the school year.</li> </ul>

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Figure 1.5 Key Participant 3=A3	
Theme and description in questionnaire on autism and its impact on families	
Emotional theme	Quotation from A3
Abandonment	<ul style="list-style-type: none"> <li>A3 reported that with his child's diagnosed and frequent tantrum, his spouse of many years walked away from the relationship. He further stated that the manner in which it was done caused him so much hurt. He stated that "Mi come home from work and find a note pon di table and the baby screaming".</li> </ul>
Denial	<ul style="list-style-type: none"> <li>He stated, "Mi neva believe a word weh dat say, so mi go doctor after doctor and a get the same report. Suh one day mi just hold mi son and cry".</li> </ul>
Feeling overwhelmed	<ul style="list-style-type: none"> <li>A3 stated "All mi do is cry and cuss God to this very day mi still cry." He further stated that the situation is very overwhelming, "I feel like I don't have any control; between the many tantrums, doctor and hospital visits, school fees and all others expenses. It's truly a lot to deal with."</li> </ul>

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Figure 1.6 Key Participant 3=A3	
Theme and Description in questionnaire on Autism and its impact on families	
Financial Theme	Quotation from A3
Salary	<ul style="list-style-type: none"> <li>A3 earns over \$20,000.00 per month which helps to go towards taking care of his son's needs.</li> </ul>
Support	<ul style="list-style-type: none"> <li>A3 reported that he receives all of his support from family members both from those who live in Jamaica and those living overseas. He further stated that his family has been his tower of strength. He stated that being a male, he felt ashamed to go to agencies begging for help for his child. He revealed that his mother encouraged him to get his son on the PATH programme, but he could not handle the level of questions that he was asked and as a result he did not continue the process. He stated, "How dem fi look pon big man and ask if mi have a fridge? I felt so small".</li> </ul>

### **Limitations and Delimitations**

In preparing any research that facilitates higher learning, there will be factors that will impede the process of collecting data and interpreting the data. There are several limitations to this study; these include:

- Gaining access to willing participants
- One participant found it difficult to trust researcher with valuable information about his child.
- Arranging suitable time and place to conduct interviews.
- The researcher is close to one of the participants and this may produce personal biases.
- The researcher had to limit the number of questions because of the nature of the study. She did not want participants to feel overwhelmed.
- This research was a small study with only three participants.
- The entire interview process took months (one participant kept putting off the interview)
- The researcher had limited understanding of how to present her data findings because it was her first time conducting a qualitative study.
- One major drawback is that the process is very time-consuming because the researcher had to stop the recorder at intervals and replay the interview many time to capture information. This is due to the fact that the programmes used to analyze qualitative research are too expensive for the researcher to purchase.
- The researcher faced a great setback in her data collection, in that; the researcher was unable to get data from the Ministry of Health. She visited the office, she called the office and she sent emails, but to date no information was given to researcher.

### Chapter 4 -Results

'I might hit developmental and societal milestones in different order than my peers, but I am able to accomplish these small victories on my own time.'

~ Haley Moss

This study allowed the researcher to examine the impact of autism on three 3 Jamaican families. Autism and its impact has long-term implications for a child's development and longevity of the family. These include, changes in financial structure of family (one parent might have to leave his/her job to stay home with the child), and abandonment by family members and friends which leads to loneliness for both child and parents.

The researcher used the data from her semi-structured interview to present the findings in this section. The semi-structured interview focused on three major areas of interest; recognition and diagnosis, intervention services, and impact on the family. The researcher will use these three areas to present her findings for participants involved in her study.

#### **Recognition and Diagnosis**

The first major semi-structured interviewed question that was asked, "When do you think autism was first recognized and diagnosed in your child?" This section has five additional questions. The first follow-up question that would assist parents to answer this question was, "How did you first learn that your child had autism and how old was the child?" All three participants gave a vivid description about the signs that led them to believe something was wrong with their children's developmental process and hence the pursuit of a physicians' professional advice. The physicians then gave the parents referrals for them to get further evaluation from specialist at the University Hospital and Bustamante Hospital for Children in Kingston. All three parents did not accept the diagnosis and as a result they took their children to see one physician after another. Parents A2 and A3 stated that their children's diagnosis was

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confirmed to be that of mildly autistic at an institution called The McCAM Child Care & Development Center off Old Hope Road in St. Andrew. Parent A1 said she knew something was wrong and she did not know what the condition was so she accepted the physician's diagnosis. All participants revealed a different age group that they noticed something was wrong with their children's development.

When participants were asked, "When did you first learn that your child had autism and what were some signs and symptoms? The following were the responses:

A1 stated, "At 18 months old I suspected that my child was not developing as a child would in his age group. He was displaying all the various characteristics of an autistic person. At that moment my mind took me back to an article I read years ago about autism. Mi seh no sah; that can't be real! Mi neva hear nobody a-talk bout autism inna Jamaica. Autism can't choose my family outa one 'woe, woe' but as I was looking at the child and comparing what the article said which I saw, I knew something was wrong. I said it to my husband and he said that he never heard of autism before.

We saw the signs, the repetitive behaviour but we kept saying no, no and so we waited, at this time he was 2 years. My husband and I decided to enroll him in school. I took my son to the pediatrician and explained to her the things I noticed, lack of speech and repetitive behaviour. I told her my fears that I thought it was autism and what cemented that is that I have two older sons to compare his development to, so I knew something was wrong. The pediatrician said she thinks that it's autism too, but not to worry it could be something else. She did speech test and some other tests that confirmed it was autism."

A2 stated, "I noticed that something was wrong with my child's development at the age of 2 because he was not doing the things that a normal 2 year old would do. My child never looked in the direction that the sound was coming from and he would always lean his head as though he was not hearing. For example; when we would turn on the television he would lean forward. He was not able to speak, make simple sentence and call words. After making all these observation I found them to be abnormal so I took him to the pediatrician. I informed the pediatrician of the things I observed. He confirmed that all these things were not normal and I should take him to the hospital. He gave me a referral to the University Hospital where they did a series of medical examinations."

A3 stated, "I never noticed any problems with my son. One thing that stood out to me is the fact that he was not talking. I never noticed anything because I was always at work and when I got home my child was sleeping. I can remember his mother on the other hand when my son was 2 years old saying

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that something was wrong with my son, but I guess I didn't want to listen or believe. I remembered one Sunday I was at home and I turned on the television but the volume was a little high, and the little boy screamed at the top of his lungs. I was so frightened. At this time my son was now 3 years old and he was not developing normally. I told my spouse to take him to Bustamante Hospital for Children. The nurse who examined him told my spouse what she suspected was wrong with my son, but it was the doctor who confirmed that my son was autistic."

All three participants revealed that they had a normal pregnancy and as a result, they were very surprised to get the diagnosis that they were given by their physicians. Two of the three parents that were interviewed recognized something was wrong with their child's development at 2 years old. One parent reported that she knew something was wrong earlier, because she used her first son's developmental process as a reference point. Hence, she started to compare and contrast both sons' developmental process and started doing her research. As a result, she did not refute the physician's diagnosis; she just had a hard time hearing her biggest fear. The other two parents reported that they had no children before and had never heard of that condition so the news was taken very hard. This was so, because the doctors told them that they would have to be responsible for their children for the rest of their lives. All three parents were able to give similar description about what they observed as abnormal behaviours for a child in that age group, hence, these caused all parents to take their children to see the physician. Some of these behaviours include: sensitivity to certain sounds, language delay, echolalia and lack of social interaction.

According to Bleicher (2013) the American Academy of Pediatrics 'recommends screening all toddlers for autism at ages 18 and 24 months.' In addition, Bleicher stated that a 'growing number of researchers believe that screening can and should start even earlier for infants known to be at high risk for autism. These high risk infants include the younger siblings of children already diagnosed with ASD.' In addition, Bleicher cited in the article that in the late

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1990s, 'Dr. Baranek began collecting home videos of 9- to 18-month-old babies, some of who later developed autism and others who didn't. Bleicher further stated that 'previous studies had shown that parents of children with autism often began reporting concerns around or before the first birthday.' Other studies of high-risk baby siblings, an area of research given special support by Autism Speaks, found that many of those who would later develop autism lacked typical social skills at 1 year of age. For example, many were not pointing at objects or mimicking their parents' (Bleicher, 2013).

Each parent was asked the follow-up question, "Did you accept the diagnosis of autism or did you disagree and challenged the physician and sought other diagnosis?" "How did you react to the news when you first learned of your child's diagnosis?"

A1 stated that "I am an avid reader and read about autism in an article. My son showed some signs of autism. After doing the tests I went into denial for a short time and disagreed with the physician even though I read and knew that I saw the signs. I asked God, why my family out of all the families in Jamaica? My son is normal looking, he is normal walking so I don't understand. Why did you choose to give my son, my family to give autism? Then I accepted the diagnosis because I knew in my heart it was autism. Even though I accepted the diagnosis it was still hard to hear the truth. It was from this process I decided to seek information and form the foundation that I did-it was coping mechanism. I never heard any parent, grandparent or friend of mine talking about autism. I was not charged with the responsibility of seeking information (a professional information seeker) to help other because I knew about the power of education".

A2 stated, "I accepted the diagnosis because I did not know what autism was, I have never heard of that condition before. Although I accepted the diagnosis, I still held on to some gleam of hope thinking that the physician incorrectly diagnosed my child. Finally, I accepted the diagnosis after I took my son to be tested at McCAM Development Center and the specialist confirmed the same diagnosis I got from the hospital. I cried as though I just heard the news that my mother died. I was in so much pain and grief I held my child and I wept openly and uncontrollably."

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A3 stated, "After 3 years of living in denial and finally looking at my son and observing him keenly I knew something was wrong, but I just did not want to accept it. When I instructed my spouse to take our child to the Bustamante Hospital for Children, I was hoping that the doctors would tell her that he is just developing slowly. When she called me and told me the diagnosis, I asked what kind of condition is that because mi neva hear bout autism before that. I was very surprised and then she told me that we need to take him to another institution called McCAM for further test. It was at that time I started to take this illness serious. People say man is not supposed to cry, but after I ended the call with spouse mi bawl and ask God what kind of curse this on my family? A lot of things started going through my head at that time. I started to wonder if it was my fault or my spouse fault why this thing is happening to my child."

According to an online article entitled *The Autism Spectrum Disorder Grief Cycle* (2017) parents go through a period of 'grief' when they are hear the diagnosis from the physician that their child has an autism disorder. The article stated that 'shock and disbelief are the first two reactions a parent usually has when hearing the diagnosis, even if they suspected something was wrong.' The article highlighted the some parents will give outburst saying, "There must be some mistake." "This can't be happening." At this point, the 'parent usually does not process exactly what has happened or the enormity of what has just been said' (*The Autism Spectrum Disorder Grief Cycle*, 2017). In addition, the article stated that 'parents often go into automatic-pilot mode and sit through the rest of the meeting without really taking in any more information.' Some parents may even feel 'physical pain,' as if someone has given them a major hit. They may feel as if they have been 'smothered in a dark heavy blanket and are unable to see or hear or breathe' (*The Autism Spectrum Disorder Grief Cycle*, 2017).

According to the online article *Autism & Your Family* (2017) parents often fail to evaluate their own sources of strength, coping skills, or emotional attitudes. Parents may be so busy meeting the needs of their children that they forget to find time to 'relax, cry, or simply think.' A parent caring for their child with autism may wait until they become so 'exhausted or stressed' that they may find it difficult to care for themselves. In addition, the article stated that

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parents must seek help in order that they preserve their emotional health. The article further stated that, people who interact with the family may want to help, but may not know how. The article encourages parents to not be afraid to accept any help they can get from the community and extended family members. 'Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning: Can they pick a few things up for you at the store or do a load of laundry? Can they let other people know you are going through a difficult time and could use a hand?' (Autism & Your Family, 2017).

It is very important that you find someone to talk with and listen effectively to your hurts or concerns. Autism & Your Family (2017) recommends that 'parents with children diagnosed with autism 'should talk to someone. Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.' The article also recommends that parents with children diagnosed with autism should consider 'joining a support group.' Additionally, Autism & Your Family (2017) suggested that parents should 'talk to people who have been or are going through a similar experience. Support groups can help to keep parents informed about coping mechanisms and services offered to assist parents alleviate the stresses of having a child diagnosed with autism.' This helps to provide hope and comfort for many parents.

According to Hill (2016) parents of children with autism go through seven (7) stages of grief:

Stage One: 'The doctors are mistaken. In this stage, you're in denial, searching for clues and proof that the diagnosis isn't real.'

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Stage Two: ‘This isn’t really happening. This is a stage of shock, during which you feel confused, numb, and disoriented. You detach from your life, withdraw from your loved ones, and feel like shutting the world out.’

Stage Three: ‘Why is this happening to us? This stage brings anger for the diagnosis and anger towards others who don’t understand the magnitude of what is happening to your family.’

Stage Four: ‘I should have done something differently. During this stage, you’ll start to beat yourself up, believing you’re to blame for your child’s diagnosis. You think that if you had done something differently, this wouldn’t be happening right now.’

Stage Five: ‘Bargaining for your child’s health.’ In stage five, ‘you begin bargaining with God, enlisting his help to influence your situation. You feel like you’ll do anything if God would just heal your child.’

Stage Six: ‘I can’t deal with this. This is a stage of despair and depression. You realize your life is forever altered, and the weight of that realization can feel like it’s crushing your spirit.’

Stage Seven: ‘Life beyond the diagnosis; this stage is a gradual acceptance and making peace with what your family looks like. This gives you the ability to enjoy parenting your child and looking forward to your future.’

Hill (2016) further stated that for parents of children with autism, move through the different stages of grief in set order. A parent may omit one stage and then and go back to that stage later, and they may ‘bounce back and forth between a few stages until you resolve them for good.’ Additional, Hill (2016) opined that the ‘most important thing is to be patient and kind to yourself as you grieve.’ And always remember that, although this painful process it will pass, the moment parents reach the stage where they are able to accept the child’s diagnosis pain

fades. And in its 'place appears a strong, unbreakable bond with the child of your reality, and that's when you can finally see how beautiful and special your life really is' (Hill, 2016).

### Intervention services

"To measure the success of our societies, we should examine how well those with different abilities, including persons with autism, are integrated as full and valued members."

~Ban Ki-moon

The second major semi-structured interview question that was asked in this section has five additional questions to obtain authentic data. All three participants were asked, "What is the nature of the intervention services received by families of children with autism?" The first question that was asked in this section was, "Name any government agency that caters to the needs of your child's exceptionality?" Two of the 3 parents interviewed reported that they did not receive any help from a government agency. One of 3 parents interviewed reported that she received help.

A1 reported that, "Current in 2017 there is limited proactive intervention personnel who discover autism in Jamaica and I am speaking from the case studies that I read. Parents with children who were diagnosed with autism must search for schools to place their children in like detectives because there is limited information about autism in Jamaica. Presently, there are more entities offering diagnostic services because the first step in getting help is finding out where on the spectrum your child falls; there are also more pediatricians who are aware of the disorder so parents are now able to move towards solutions. In terms of telling you that there are ten (10) government schools across the 14 parishes that specialize in autism, I was never able to find any at the time of my son's diagnosis. I have never found a bank of specialist for example teachers and doctors or even an autistic center that provides help for parents and their children. I was one of those persons inadvertently breaking ground and pioneering a lot of stuff and kick starting a lot of stuff just by starting the conversation. Five years ago I checked in with the Ministry of Health to garner statistical information about autism. They reported that there are 5 autistic children in Jamaica which I thought was ridiculous. No way can this report be accurate; there is no M.O.H report that

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is accurate on the status of autism in Jamaica. So to answer your question, I do not know of any government agencies that assist families with their autistic child.”

A2 reported, “I do not know of any government institution that caters to autistic children. Presently, my son is attending a private institution but it is very expensive. Although it is costly, I have to no choice but to let my son remain at this institution. The government does not provide schools or learning centers that parents can go to for help for their children with autism. For me, the school is the first point of intervention that I know my child will get the necessary help that will cater to his needs. On the other hand, there are government agencies that give financial assistance to parents with autistic children, for example, Early Stimulation on Hanover Street, The Jamaica Council for Persons with Disabilities on Ripon Road and also The Special Education Unit at the Caenwood Center. I know about those 3 places because I have gotten help from them and 2 of the places I am them still getting assistance for my child.”

A3 reported, “I have never received any early stimulation help for my child from any government agency, all the responsibilities fell on me as the parent. I cannot name 1 government owned school in Jamaica that caters to autistic children, and it is very expensive to have my son schooled in a private institution. I know that Jamaica is not as developed when compared to other 1st world countries like the U.S.A, but the Jamaican government can do more to assist parents with children diagnosed with autism. I took out National Health Fund card for my son because I found out that he has asthma I also tried getting him on the PATH programme, but I was turned off because the persons working in these offices don’t treat parents like human beings and this heightened my stress level and made me very angry.” A3 was asked to give a little more clarity on his statement about PATH, and he responded by saying “One lady looked at me and said to another co-worker, but this man don’t look like him need to put his child on PATH. As a result of that I left the office and never returned”, I was already feeling disheartened and stressed and to be truthful I did not want to be disrespected by these ladies.”

In any country the government must provide and protect its most vulnerable - the disabled. I believe that the Jamaican government must put in place the necessary infrastructures to help the families and their children diagnosed with autism to reach their fullest potential.

Wilson (2011) cited in an online article that Leonardo's parents, Sharon and Lloyd Davis, ‘found out about his condition when he was just a month old, and since that day, they said their lives have not been the same.’ Leonardo is now eight (8) years old and lives in Clarendon. The

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parents were unable to find a school in their parish to place Leonardo, because there are no schools designated in Clarendon to handle children with autism. They have been faced with many challenges to find a school that will take their son. Davis said his son was ‘refused admittance by several schools for much of his early years, which led to him being inducted in the formal school system just two (2) years ago at six (6) year old’ (Wilson, 2011). In addition, Wilson (2011) stated that Davis and his wife are financially and physically drained from caring for their autistic son. They believe the establishment of a school for autistic children in the parish or in nearby parishes, would go a long way in getting him the specialized treatment he needs, so he can lead a life as close to normal as possible (Wilson, 2011). According to Wilson (2011) founder of the ‘Maia Chung Autism and Disabilities Foundation (MCADF), Maia Chung, said the few schools that cater to children with autism in the island are overcrowded, given the increasing number of children being diagnosed with this disorder. Most of these schools are also based in Kingston, with the exception of those run by the Jamaica Association on Intellectual Disabilities (JAID), which caters to children across the island.’

It is therefore imperative that the government of Jamaica create the necessary facilities and the necessary intervention programmes, to help alleviate some of the stresses that families face with their children who are diagnosed with autism. Wilson cited the article that Chung stated that one major problem to create schools that specializes in the teaching and learning for children with autism. Another major problem is that there are no ‘real statistics as to how many children diagnosed with autism in the island. Additionally the article stated that statistics showed in 2005 that there were two (2) children with autism in Jamaica, ‘although experts have speculated that it could be thousands now based on those who come in for diagnosis.’ Precise

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empirical data would help all stakeholders to ‘determine the level of intervention needed for treat’ children diagnosed with autism (Wilson, 2011).

Williams (2016) in an online article stated that the ‘Minister of Education, Youth and Information, Senator the Honourable Ruel Reid, is looking to work more closely with the Jamaica Autism Support Association (JASA) to better address the needs of children with autism.’ The article opined that the Minister of Education, Youth and Information, Senator the Honourable Ruel Reid, invited the respective authorities from JASA to have a sit down so that they can find ways to enhance and expand the programmes offered at JASA to further help families with children diagnosed with autism. Williams cited in the article that Mr. Reid said that ‘he believes that all our children deserve an equal opportunity to learn.’ (Williams 2016).

When asked, “Describe the extent to which you have benefited from their services and how do you feel about these services?”

A2 unequivocally stated, “Jamaica Council for Persons with Disabilities they assist with school fees, uniforms and book grants, but the only drawback is that parents only get help at the first term because they too are faced with financial challenges so they find it impossible to give parents financial assistance for the 3 terms. I am grateful for this assistance, but being a single parent, it is extremely expensive to keep my son in the school that he attends. A2 was asked, “How much do you pay for son’s school fee?” She responded “for my son each term I pay \$65,000.00, (and keep in mind the school fees are increased every year). So, after I get the assistance at the beginning of the term, I have to struggle to find the other 2 terms and this does not include lunch and transportation for him”. The Special Education Unit has also assisted with a percentage of the school fees for my son, but that assistance has cut back now because the unit is under grave financial constraints. In addition, I find the assistance helpful especially in the 1<sup>st</sup> term with the back-to-school. After purchasing books and all items that my son needs can be very taxing. Due to these factors I run short on finding all the school fee – remember the school fee is very expensive so the financial assistance it covers a huge gap by taking some of the stress off me. To be honest, I can’t be ungrateful or even complain, because without this assistance (however small) I don’t know what I would do.”

When asked, “What services have been most helpful to your child’s development?”

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A1 revealed that, “At the time when my son was diagnosed, the condition was like a phenomenon and as a result of that I have never received help from any government agencies. I had to go out and seek information to help my family”.

A2 stated, “The only service I receive is help from Jamaica Council for Persons with Disabilities and The Special Education Unit which I am thankful for so those are the 2 agencies that assist me with my child. I think however that the medical aspect of taking care of child with autism is very stressful and will cause financial strains for me. I believe the government of Jamaica should do more for parents with a child diagnosed with autism as it relates to this aspect. For example, my son has to do another surgery and he has done 2 surgeries before because his adenoids keeps growing back blocking his airway, this hinders his breathing especially at nights (sometimes I am afraid he will die in his sleep). He did the first surgery at The Bustamante Children’s Hospital and that was free, but it grew back, I decided

that I would have to go and get the second surgery done privately because the waiting list at Children’s Hospital was just ridiculous. The length of time I waited he has now passed the age that the hospital would do his surgery and there is no other government hospital that would give the surgery free without him being on a waiting list. If I had sat and waited on the hospital to reach my child he would probably be dead by now because his situation was so severe. The cost to do the surgery privately was very expensive, I had to take out a loan just to finance his surgery. There is no hospital in Jamaica that caters to families with children diagnosed with autism who also have additional medical conditions”.

A3 revealed, “I have received no support from a government agency, but JASA was my life line. All I wanted to do was off load some of the things I was going through- with my spouse abandoning her child and walking from our relationship of 7 years was a heavy burden to carry. I not rich but I able to handle the financial side, I was unable to handle the emotional and psychological aspect of having a child diagnosed with autism and that’s where JASA plays its most important role. They provide workshops, help speech therapy but most important they cater for parents who are struggling in more ways than one.” The school that my son attends is not a government owned institution but has moved him from being none responsive to responsive. I can sometimes see his eyes sparkle with excitement.”

It is imperative that parents seek for the necessary information that will help them cope with their children diagnosed with autism. The onus is on the parent to find what government agencies that exist in Jamaica to help alleviate some of the stresses that are associated with a child diagnosed with autism. According to an online article, Council for Persons with Disabilities Expects Increased Registrations (2015) since ‘the passage of the Disabilities Act in 2014, the

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Jamaica Council for Person with Disabilities (JCPD) has been calling for persons with disabilities to become registered and enjoy the benefits of being a member of the council.’ It further stated that these benefits include ‘economic empowerment grants, assistance with assistive aids and devices, as well as therapy sessions and the concessionary bus fares with the Jamaica Urban Transit Company (JUTC).’ In addition the article stated that in ‘specific cases, income tax exemption is also included.’ The article cited that Hendricks said there have been challenges because some people do not accept that they have a ‘disability out of fear of being stigmatized and labeled’ (Council for Persons with Disabilities Expects Increased Registrations, 2015).

The Jamaica Autism Support Association is a parent support and advocacy organization that helps to support parents with children diagnosed with autism in many ways, for example; ‘workshops, raise awareness about Autism in Jamaica, early screening, and funding.’ According to Jamaica Autism Support Association (2017) article in April 2006, the ‘Rotary Club of Kingston, UNICEF, the Kingston YMCA and the Early Childhood Commission in collaboration with the group of parents, held an Autism workshop with the main objectives being the education of parents and professionals on autism and the establishment of a Parent Support Group.’ The Jamaica Autism Support Association (2017) opined that the ‘first official meeting of JASA was held in 2007. In addition the Association stated that, meetings are held regularly on the last Saturday of each month at the Kingston YMCA.’ The goals of JASA are as follows:

1. To raise awareness about Autism in Jamaica
2. To assist in research on the prevalence of autism in Jamaica
3. To advocate for Action, Intervention, Accommodations and Solutions: Tax Relief for Autism individuals and families affected, Early screening, Free health care, Occupational

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Speech and Physical Therapy, psychiatric and psychological care, Subsidized education (parents to only pay the same as all others, no extra for special care), to take the steps necessary to have an education system in Jamaica that is inclusive for our children, Funding, Training and Support (Jamaica Autism Association, 2017).

When asked, “What impact has the services had with regard to your stress and coping?”

All participants reported that the most helpful services were financial, support group and the schools that their children attend. Parents revealed that these services greatly reduced their stress level and helped them to cope with their children’s disability. One parent however stated that he was turned off from a government services because of the way he was treated and this heightened his stress level.

Parents were asked on a scale of 1-10 which service impacted your lives the most all 3 participants said the schools; examples of the impact included:

A1 “The speech therapy and all the other social activities helped my son to the point where he was able to sit his grade 4 Literacy and Numeracy exams, he also sat his GSAT and passed, he is now going to do his CXC exams. I also use my son as a case study to help map and structure programmes that will help other parents.”

A2 “As we speak I reflect on how much my son has improved, he is able to show emotions if his tommy hurts, he would sit in my lap and say, “mommy my tommy hurts”. He will hug persons with whom he is familiar with and have small conversations. The teachers and specialists at his school reassured me that I will see even more improvements in his behaviour and speech and that warmed my heart. I feel like there is hope. This school has helped to reduce my stress in so many ways. My son is now being prepared to sit the grade 4 Literacy and Numeracy exams and to tell you the truth; I never knew that this day would come. So right now I am feeling so proud of his little achievements”.

A3 “My son’s school and JASA have been my tower of strength. These two bodies helped me to cope and helped to alleviate some of stresses I face on a daily basis. Even though my son is not speaking clearly he has started speaking. He is now able to respond to commands, for example, give daddy a hug, or come here, or he is able to say if he is in pain. He has a friend at his school that he shares his snacks with and they are socializing”- He smiles as he speaks, “I don’t know what they are

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talking about but when I go to pick him up from school they are together and I think that is good. I feel a sense of peace knowing that my son's school is doing such an excellent job preparing my son for the next milestone in his life. JASA as I mentioned before allows me to interact with parents who also have children diagnosed with autism. I can sit and pour out my all in the meets and no will judge me or turn up their noses at me and my son. ”

“It takes a village to raise a child. It takes a child with autism to raise the consciousness of the village.”

Coach Elaine Hall

Autism and all the symptoms that come with it can have a negative impact on families and their children. Some parents prefer to leave their child diagnosed with autism with caregivers when leaving home to go on the road than to face the many social rejections and challenges in public places. The three families that were studied found a myriad of ways to cope with their children diagnosed with autism. One of the common coping mechanisms was having someone to vent all the difficulties they were facing at the time. These persons were willing to listen and give comfort in when things got overwhelming.

### Impact on the family

The final interview question was, “What has been the impact on the family of having a child diagnosed with autism?” Parents were asked seven specific questions to guide into answering the final major research question. The first question was, “What have you learned from raising your child with autism?” All three parents revealed that they have learned how to be patient and tolerant especially when their children being to throw tantrums. Parents also shared that they have learned to become more patient and tolerant of others as well. When the situation gets overwhelming, you as the parent must take some deep breaths and count to ten. For example;

A1 shared, “A crocus bag of things, (smiling) apart from learning to be patient with my son, I learned a lot about the medical and education aspects of autism. I became more educated about the

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disorder; I know what the characteristics are but I will never be arrogant enough to just point out someone and say out right that this person is autistic. If I have a close friend and the spouse displays some of the characteristic of the disorder, I will pinch my friend and let her know, worse if they are having problems. Some people are autistic and are powering on better than us. I learned a lot about the science of autism and that has assisted us in structuring our home and our processes to make it more comfortable for my son.”

A2 shared, “I have become too attached to my son I cannot say that I will overcome this attachment to him. I have learned to love him extremely, I am at the point where I think for him in terms of the type of foods that he would want to eat, the type of toys that he would want to play with, anything that he would want I would say that this is good for him. I don't know if what I'm learning is good, because I'm of the point where I would want my son to be independent but I still bathe him. I still wipe his bottom because when he does it I don't think that he is doing it properly, and I want my son to be clean and smelling good. I have learned patience but I don't know how much of it I still have, seems that I want to bring him to a point of independence. So every time he comes to talk with me about what he is doing, I might say, son, ok go now, go and do this but still nevertheless I try to calm myself especially when he throws tantrum I try to sit and calm myself and do self-talk (listen to mi I have to have patience this too will pass). I also have to have self-control but to be truthful sometimes I might not have any of the two with my son sometimes and so I still get angry asking, Why is this my child? Why do you have to behave like this? If you tell a child to stop the talking the child will stop talking. My son will not stop talking. He is going to talk back and throw a tantrum. But when I am at work and I say to a child stop the talking and that child does not I have the patience to deal with that child at work, because my son has taught me tolerance.”

A3 shared that, “I have learned patience and tolerance because when my son begins to throw his tantrums I have to walk away or just sit and watch the television and allow the more to past. In the initial stage of dealing with my son I would sometimes shout at him or even slap him and after I did any of those I felt bad inside because I know that it's because of the disorder and I should know better. I can recall taking my son to the supermarket one Saturday he want me buy some random thing and said son put that back on the shelf-my dear I tell you now lie, my son screamed and screamed but this time he started hitting me. Persons in the supermarket started making all kinds of comments” for example; “look pon di big man a tek lick from him son, this is reason Jamaica is like this now”. “All I could do was to lift up my son and leave the supermarket while driving he started settling down because he loves being in the car.”

Campbell-Livingston (2017) cited in an online article that parent Hunter-Lowe ‘feels resentment now and then because they often have to hide her child’s disability and see it as something shameful. The fleeting thought of finding her child annoying, or resenting the loss in

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time for herself, can make her feel inhuman and disgusting to the core.’ She adding, that mothers must move away from being ashamed of their child to feelings of acceptance. Mothers must also try to forgive themselves for feeling the way they do. She further stated that, it is a ‘fact that mothers sometimes experience a sense of guilt as there are times they feel resentment about the situation they are thrust into.’ In addition, Campbell-Livingston opined, that from ‘observation and experience, parents are always stressed out from dealing with the everyday responsibilities of children with autism.’

When asked, “How has the family dealt with this diagnosis and in what ways has this impacted the family?” All three parents shared that their family and support groups were their tower of strength and without them being their biggest cheerleaders they do not know they would have coped emotionally and financially. Examples of parents’ responses include;

A1 shared, “I am from a Christian family and my family is tertiary level educated, so, in all things we put God first and then we use our wisdom to guide us. We try to put our son’s needs first and what my son says that’s how it is because he is the king of my household. My son’s diagnosis caused the family a financial strain to the point where we are bankrupt. I must also say that my son’s diagnosis placed a great deal of strain and stress on the family to the point where my husband and I got a divorce. I find that now a lot of women come to me because autism breaks the family. Where I was in my zeal dealing with my son’s disorder I don’t think my husband was, and that caused a disparity in a husband and wife relationship, and so we grew apart, and I think that is one of the biggest impact. A positive impact is that all my sons’ work together. In the foundation, we have pioneered a global award.”

A2 shared, “My family has come to accept my son’s diagnosis and they love him and he gets a lot of love. I try to do whatever the doctors recommend I should do and I try to follow up with his doctor’s visits, I also try to give him the type of foods that is healthy for him and try to be patient and kind to him. My son’s diagnosis is very stressful in every aspect. The financial aspect of it is ‘killing’ but what am I going to do? I have to make it I have to find a way how to survive and for him to survive. So, it does not necessarily means that it is going to be the most expensive way, but in my own way and in the way that I can finance things-I just try to make it work. One thing with my son is that he loves attention, example; there are times when he comes and stand in front of me and he wants me to look straight into his eyes. He wants me to look at him, he would say; “Look at me mommy when I am talking to you.” I have to realize that he is here already and he is not going anywhere and I am going to have to deal with it. So

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even though it is stressful most times I just brace myself and say ok another day is here and just move on. When I go into his space that's the time things get terrible because he wants his alone time and does not want to be bothered." Overall everything has to be routine and I have to stick to it, because any day I decide that I am going to do things differently, nothing will get done that day because my son loves routine.

A3 shared, "Dealing with a child with autism is very stressful, they can be stubborn and they throw lots of tantrums, but I try not to shun my son, I deal with the situations as they arise. The great thing about having a family that cares is that they are always willing to help in whatever way they can. And to be honest my mother taught me to love my son unconditionally. My brothers and sisters are always there to help especially when my son is to be picked up from school most days. They even show more patience and tolerance towards my son than I do I am so grateful that they are in my life. One of the most significant impacts is that my spouse of many years left the relationship because she could not handle my son's tantrum. It was a constant blame game between the both of us, so, one day I came home from work and she was not there. When my spouse left, it broke me I couldn't even look at my son. "It was my mother who reached out and held me"-sniffing.

Parents were also asked, "How were you supported by the extended family and what role(s) have they played?" Two parents stated that their family is their tower of strength and without their family they could not have coped. These parents revealed that their brother, sister, aunts and uncle, were very supportive in more ways than one. Having a child with autism can be extremely stressful and that stress can double without having support. One parent shared that she became the person to helping her extended family, because they have never heard of the disorder before.

A1 disclosed, "In the initial stage they were clueless about autism and its symptoms so they were not sure of how best to help. I couldn't lean on them for help because they were not informed so it me who was helping them. There is heavy research now to show that autism is genetics and with that I have another little nephew who is autistic, so now the family is able to speed up the game of helping and supporting each other and to assist the child better. So for me, it was more a matter of me teaching them and as I learned I spread the information to them and to my foundation."

A2 disclosed that, "My mother has always been there for me, she was the one who told me to go and get my son tested to find out what was wrong with him. And from that day to now, she has been there to support me in any way she can; she picks my son up from school, she cooks dinner and washes his clothes. I am so grateful for her words and cannot begin to explain. My brother is also very supportive he

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will care for my son when my mother has errands on the road to do; he also picks my son up from school. I have to work so most of the other things that need to get done they will fill in and get it done. My aunt also helps financially and this goes a far way, for example; to buy food and clothes for my son. My aunt also calls and talks with my son even though he is unable to hold a conversation, but I appreciate her for doing that. It shows that she cares about me and my son.”

A3 disclosed, “My family is supportive to the point where aunt, uncles and sister overseas send money every month to help with my son’s expenses-having a child diagnosed with autism can send a family into financial crisis. So those additional funds are used to help pay school fees, purchase lunch and school books. Every so often they will pack a barrel with food stuff, clothes and toys, so there are some things I don’t worry about. My mother is the person who takes my son to school in the mornings and I pay a bus driver to take him home. My mother will stand at the gate when it’s near the time for my son to reach home and collect him. My mother bathes my son as soon as he gets home from school and gives him a snack. I don’t have to worry about preparing his meals. One of my sisters helps with that part. I ensure that I am at home to feed him dinner because he will not eat dinner from my mother or sister, because he has gotten used to me feeding him. So I can say proudly that my family is my backbone as it relates to my son.”

Another interview question that was asked is, “What are your coping mechanisms?”

All parents revealed that they must find ways to cope with having a child diagnosed with autism. Without finding coping mechanisms they would have given up on their children and walked away. Parents gave strategies they used to help to cope with their children’s disorder, for example; faith in God, exercise routine, home routine, child’s school family, support groups and family members.

A1 shared, “My first coping mechanism is my faith in God, that’s how I ended up forming a foundation. My faith in God saw me taking on the mantle willingly on the premise of you seeing your brother helping your brother sow seeds into your brother, so that you can reap seeds of your own. I sow every seed into the foundation, so that I can and reap on behalf of my son, as an intercessor. My foundation became the first in the nation of such type. It helps me to focus on others in the same situation, as I help my son. By choosing to help and share information about autism, it keeps my spirit up, I also try to help other in a proactive way to the point of legislation as cabinet appointed me to advise the minister of disabilities on issues relating to autism or case studies, anecdotal research and intervention over a number of years, and that is how I cope-I go to church a lot and I do Dojo.”

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A2 shared, "Firstly, I must say that my child's school helped me a lot with my mental state, because the school provides sessions where parents can sit and talk about what is happening to their child. The school also invites presenters who will come and address any problem that a parent is having and so I feel very comfortable going there and having honest conversation with other parents. Secondly, I turn to my Jesus in prayer. Although I'm not a Christian I find myself wanting to be in the presence of God and I do this by going to church and asking church member to keep me in their prayers. This gives me a sense of peace, knowing that I have a greater power taking care of me. I also have a routine that I stick to and never fall out of it. So when my son gets up in the mornings I bathe him first; then I give him his breakfast; then I give him some time for himself so he can do whatever he wants to do and then that's the time I to relax, meditate on God's goodness and watch television. When its lunch time, I give him his lunch. If he has homework or projects to do, I will say to my son, it's time to do your homework, he will rebel but I have to speak to him calmly, rub his head and tell him mommy loves you son come and sit with mommy and do your homework and that's the time he calms down and sits with me. Thirdly, my darling mother helps me to cope more than I can say. She has stood beside me, behind me; she has walked with me, and held my hands on days when I'm too weak to carry on. She has taken on so much of my pain, and I worry about her, but most of all I give God thanks for her. Where would my son and I be without my mother?"

A3 shared, "Attending group meetings at JASA, and I hear parents share some of the good things that are happening with their children, I am encouraged and I try different things to help my son keep calm. After trying new methods with my son and see him do things that I never thought he would, it amazes me. For example, I started hugging my son and rub his tummy and that calms him down. If I don't give my son a hug in the mornings before he goes to school, he will come and say, daddy, hug me.

According to Campbell-Livingston (2017) 'parents cope with the grief, worries of the future, and the uncertainty about what really caused their child to be autistic/disabled, as well as possible guilt that something they have done caused this to happen.' In addition, Hunter-Lowe stated that parents must also take care of themselves because the stress can have a huge impact on quality of life for anyone and is essential for parents of children with autistic behaviours. Additionally, the article stated that they need to get 'plenty of exercise, a lot of rest and sleeping time, regular medical care, healthy eating habits, spending time with friends, and doing plenty of outdoor activities' (Campbell-Livingston, 2017).

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The final question asked in this interview was, “How is your relationship with your child now?” Parents reassuringly stated that they have grown to love and appreciate their children.

A1 shared, “My son is my world, and he is like a king in my home. Whatever he says, that’s how it goes. Bwoy mi love him so till mi fool and that’s how I feel about my three sons, it’s fantastic. I treat him no differently, we hug and kiss so many times throughout the day that when my mother was alive she would say that I am going to damage my son, because what I was doing is really weird. My mother would also say that I need to ease up off my son and let him be a man. It’s very funny because autism is supposed to be very android robotic type of emotions, but my son is very huggy as trained by us. But when they are trained like that they constantly want to be hugged and kissed. My relationship with my son is excellent and he is going to higher heights because as I said, he is now preparing for his CXC’s in Mathematics and Accounting. He is very happy and well adjusted.”

A2 shared, “My relationship now with my son is excellent, but like I said before, we are so close that it is wearing me down, I want him to get to a point of independence, where for example I might want to go on trips that my school may have but I feel so guilty leaving him at home and knowing that I’m gone to have a good time and he is home on the phone or watching the television. Our relationship is really good but I just worry about him coping with life. However, I feel so nice sometimes when he is calm and he is in a good mood and we are able to have a conversation and he is able to respond to back to me in a way that is favourable to me.”

A3 shared, “My son has become the teddy bear in the family. Everyone looks out for him, because he is very loving. He loves being hugged and pampered. I have a great relationship with my son. When I look at him I see me. Autism tried to steal my son, but I’m fighting back. I just have to continue to learn more about the disorder and grow in understanding how to deal with my son and his many challenges and moods, so I am able to pick up on them and address them as we go along.”

## Chapter 5: Conclusion and Recommendations

"Child of mine, child of mine, Oh yes, sweet darling so glad you are a child of mine nobody's gonna kill your dreams, Or tell you how to live your life, there'll always be people to make it hard for a while, but you'll change their heads when they see you smile."

- Carole King

This chapter will give a comprehensive view into the lives of three (3) Jamaican families with children diagnosed with autism. The researcher will use her interview questions to guide her discussion on autism and its impact on the family. The discussion will also take into account coping mechanisms for parents and therapies and other methods used to improve the life a child diagnosed with autism.

A child diagnosed with autism is able to learn and reach set goals in his/her own time; with the necessary support from their family members. Like other children, a child born with autism is also able to show affection. Once the child who is diagnosed with autism is taught he/she will never fall out of that routine. Having a child diagnosed with autism, does not mean that the child will be unable to function, but with the right interventions and strategies the child will be able grow and work at his/her own pace.

According to the Batema (2017), intervention for autism is meant to 'decrease behavioural problems while increasing independence; this kind of treatment, however, takes time, often twenty (20) or more hours a week, including one-on-one instruction and support from family members.' The online article noted that 'not all children with autism struggle with the same areas of development and according to Bright Tots, some children with autism have exceptional abilities.' Common special talents include 'strong memory, musical ability, math skills or the ability to focus on one particular interest. About one in ten (10) children with autism have a particular skill they excel in, often above and beyond their peers.'

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The researcher garnered from her research that it is imperative for parents to get their children tested once they recognize there is a problem. Parents must also follow through with the treatments that their children must get, so that the therapy at the beginning of administration can be effective. The support given to children born with autism is very important, this will help them to succeed however small, and reach their milestones on their own terms.

Edwards (2014) stated that Jamaicans are being encouraged to play a 'greater role in protecting the rights of the disabled, and helping to remove the barriers to inclusion, participation, and development of persons with disabilities (PWDs) in the country.' She further stated that, this call comes from 'Executive Director of the Jamaica Council for Persons with Disabilities (JCPD),' Edwards cited in the online article Christine Hendricks, who noted that without a 'national drive to ensure the protection of the rights of persons with disabilities, they will continue to be dependents of the state.' In addition, Edwards opined that the 'disabled will forever be on welfare; their potential and their value will be untapped; Jamaica will never benefit from their creativity; and Jamaica's true potential and developed status will only be a dream.'

This study provided the researcher an opportunity to get firsthand knowledge into the lives of three (3) families with children diagnosed with autism. The researcher structured her study so that she was able to get pertinent questions answered. She prepared questionnaires that allowed her to garner demographic information, and also semi structured interview questions that gave parents a platform to speak openly about the impact autism has on their family.

The semi-structured interview questions explored 3 important areas that helped to guide the research; recognition and diagnosis, intervention services, and the impact on the family of having a child diagnosed with autism. The researcher will discuss each area under the headings in their entirety.

Recognition and diagnosis

Two of the parents who participated in this study saw signs that something was wrong with their children but were unsure of the problem their children were having. The other parent was unaware of what was happening with his child. After diagnosis all 3 parents did not accept the diagnosis readily. The findings from the study highlighted that the mothers had a normal pregnancy with none of the children being born prematurely. Parents also did not recognize the problem until the children were between ages eighteen (18) months to two (2) years old.

According to Hutton (2002) some children appear to ‘develop normally for a period of time, then lose early communication and social skills or fail to develop more advanced language and social skills. Pediatricians, language and communication pathologists, and in some cases teachers, who may see children in clinical or classroom settings, can sometimes detect the indicators of autism as young as twelve (12)- eighteen (18) months. In most cases, the indicators of early childhood autism are generally the most clear at two (2)-three (3) years old.’

The interviews with the parents revealed that although physicians had an idea of what was happening to the children, they made recommendations that the parents should take their children to external agencies to conduct comprehensive tests, so as to get a correct diagnosis of their children’s condition. One such agency that stood out was the McCAM Child Development Center.

The interviews also revealed that parents knew something was wrong but they were never expecting the diagnosis that was given. The parents did not accept the diagnosis of autism at first and challenged the results. Parents also tried to find answers by seeking other physicians’ advice. Parents expressed feelings of abandonment, denial, stress, constantly crying and fear, also feeling

overwhelmed after the diagnosis. Although the diagnosis was overwhelming for parents, they tried to seek help for their children, so that, they would be able to function as best as possible in society.

According to the article *Effects of Autism on the Individual and their Family (2017)*, parents can become ‘isolated, depressed, and emotionally and physically exhausted from looking after their autistic children and fighting for support.’

While conducting the interviews the parents expressed feelings of frustration not knowing what was wrong with their children in the initial stage, and then finding out at the age of approximately two (2) years old after getting the diagnosis done that their children was autistic. It is imperative that parents observe their children keenly and have them tested so that they have an early diagnosis, this is will propel the process of finding different intervention programmes to help their children cope. It is equally important that doctors make themselves au fait with the symptoms of autism so that they are better equipped to make a diagnosis rather than sending parents to different institutions to get the diagnosis done. In some cases the institutions that are used for testing children for disabilities are sometimes under staffed and have a long waiting list, while others are very expensive and some parents find it difficult to pay for these services.

According to Douglas (2007) in an online article in the Jamaica Observer ‘parents wishing to have their children are tested for a range of learning disabilities may have to wait for up to four months before such tests are done because of the high demand for the service.’ In the Jamaica Observe The Mico Child Assessment and Research in Education (CARE) Centre, the ‘only public institution of its kind, has seen an increase in demand for its services, despite efforts to expand its reach across the island over the past two (2) years.’ In addition, Douglas stated that

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the center provides diagnostic testing and offers remediation services for more than 1,000 children with learning disabilities per year, which is up from an average of 500 in the 1980s.' the Mico University College also provides training for individual who wish to pursue their studies in the 'special education. '

### Intervention services

After diagnosis, it is also imperative that parents be given counseling upon receiving the diagnosis that their children are autistic. This is so because the symptoms that come with autism can be very hard for the parents to handle. As a result, parents will need emotional help to cope with their children's diagnosis. Parents should also try to prepare themselves with as much knowledge about the disorder as they possibly can. This may be done through reading and finding different support groups. Support groups help to build the parents confidence and also help to them to listen to other parents talk about different coping mechanisms that are useful. Parents who were interviewed revealed that support groups at their children's schools helped them to better understand their children's disorder and helped them get their children into programmes to build their children holistically.

Intervention services provided by the state should be made easily accessible by all parents, without gender bias. Each household should be able to identify government agencies that grant assistance to parents who have children with disability. Most parents in the study were unable to tell of services offered by the Jamaican Government that helps to mitigate their stress level and help their children. One parent even felt as if he was discriminated against after he attempted to access service that would help his child. Another parent was aware of the different channels that she could take because she is an educator.

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According to Wilson (2012) four years after the Maia Chung Autism and Disabilities Foundation (MCADF) was launched to help children diagnosed with autism it is set to discontinue all forms of outreach activities, effective today, citing Government's obvious disregard for those living with the mental disorder. In addition, Wilson stated that Chung was motivated by the diagnosis of one of her three sons with autism. Chung established the foundation to lobby for children suffering from the developmental disorder, which impairs social interaction. The MCADF has organised various fundraising initiatives geared toward helping to subsidise care, medication, school fees, and even groceries for parents of autistic children.

While conducting the interviews the researcher was made aware of some services that the Jamaican Government assist parents with, but some persons are unaware of the services, while some are not accessible in certain parishes. There are government services that provide parents with grants to assist with uniforms, books and school fees, but from the study conducted, children who are need of behavioural therapy and speech therapy would need to be placed on a waiting list before they can be given help. As a result, parents must find alternative ways of seeking help to care for their children diagnosed with autism.

It is equally important that the Jamaican Government create more special education schools to help alleviate some of the financial stresses that parents with autistic children undergo. From the interviews conducted, parents revealed that the schools that their children attend provide them with speech therapy and behavioural therapy. Parents were quick to highlight that the schools their children attend are privately owned and that there are no schools in Jamaica that caters to their children's disability.

According to Wilson (2011) parents Sharon and Lloyd Davis 'found out about their son's (Leonardo's) condition when he was one (1) month old, and since that day, their lives have not

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been the same. With no school special education specials in Clarendon specifically to handle children with autism in. as a result they have been finding it difficult to place him in a school (Wilson 2011). In addition, Wilson stated that Leonardo was ‘refused admittance by several schools for much of his early years, which led to him being inducted in the formal school system just two years ago at the age six years old.’ The highlighted that the Davis is thankful to the ‘administrators of Chapelton All-Age School in Clarendon’ because they accepted their son in the institution, and ‘his teachers there have been trying to make life as normal as possible for the youngster in order to get him to fit in with his more advanced classmates.’ This has been a mammoth of a task, as ‘Leonardo has a short attention span and problems interacting with his peers’ (Wilson, 2011).

Due to lack of services offered by the Jamaican Government coupled with the long waiting lists, parents become frustrated and even overwhelmed with not knowing where next to turn to get help for their children.

#### Impact on the family

All 3 parents that were interviewed revealed that having children with autism is very stressful. But sticking to a routine helps to minimize the stresses because children with autism love routine and this helps to function. Parents revealed that equipping themselves with knowledge about the disorder helps them to understand how to address some of the many tantrums their children exhibit.

The impact of having a child diagnosed with autism on the family is overwhelming. Parents must put plans in place for taking their children out, such as to the stores, and also finding time for themselves to recuperate from a stressful day. Parents revealed that their children need to be constantly supervised and as a result they are unable to leave their children to

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go on even staff trips without worrying about their wellbeing. All three (3) parents that were interviewed referred to being stressed and feeling overwhelmed because they constantly worry about their children with autism. Parents revealed that they have become so attached to their children and this adds to their stress level. Padden & James (2017) opined in an online journal article that ‘parents of children with Autism Spectrum Disorder (ASD) have been reported as experiencing higher levels of stress and poorer physical health than parents of typically developing children.’

Although parents spoke of how stressed they are, they also revealed that their children have taught them to be patient and tolerant- showing patience and tolerance for others, their children and themselves. Interestingly, parents revealed that although having a child with autism is very stressful they have learned to love their children extremely, to the point that they are able to think on behalf for their children and speak for them no matter their age.

Some parents are at the stage where they want their children to be independent, because they are fearful about what will happen to their children when they get old or should even die- although other family members will step in and help. Parents pointed to the fact this is a sore point for them, to be constantly worrying about ‘what if?’

Autism and its impact on the family can have a dreadful effect. From the interview, parents shared that an unpleasant consequence is that autism can break the family. However, on the other hand they stated that it can make the family closer. All parents that were interviewed gave chilling accounts of how spouses of many years walked away from the relationship because of all the emotional, financial and social pressures that are placed on the family.

The extended family (grandparents, aunts, uncles) plays an integral part in the support system for parents with autistic children. Grandparents, aunts and uncles were the ones who

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‘stepped up to the plate’ and helped parents with caregiving, financial assistance and emotional support. Participants revealed that these extended family members went beyond the call of duty for them by taking their children to school, helping to prepare children for school, and picking up the children from school, paying school fees and taking care of any other duties that were called to do. Participants spoke of their mothers in high esteem. One participant said her mother was her tower of strength and she could not have carried on the fight for her child without her mother. In the online article Autism Speaks (2017) stated ‘like the parents of children with autism, grandparents can have different reactions and responses when they learn their grandchild were diagnosed with autism. Grandpa to a four (4)-year-old autistic boy who I totally adore stated I’m the “go-to” person when his Mom is struggling to handle the work and pressures of William’s conditions.’ The article cited that William’s grandpa find that he has his trust in areas where his own parents are unable to garner that William’s trust. To help support his grandchild and family grandpa’s ‘license plate includes the autism puzzle symbol and says “4Will”. Together with Williams parents, his preschool teachers and me (Grandpa) we are making great strides’ (Autism Speaks, 2017).

The research was conducted to provide information to policy makers, principals, teachers, parents, researchers and other stakeholders. Autism is not something separate and apart from the society. It has its impact on the home and society at large. However, the child diagnosed with autism will be greatly affected, and who is likely to become an ‘an outcast’ in society if not helped at an early stage.

The prevalence of autism is increasing instead of decreasing, hence the necessity of all involved to become aware of what autism is and how to implement and utilize programmes help children with autism and their families cope. According to the online article Autism Speaks

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(2006) the Center for Disease Control and Prevention (CDC) estimates autism's prevalence as 1 in 68 children in the United States. Ozerk (2016) opined it is very clear that for the period from 2000 to 2014, the prevalence of autism ASD at the national federal level has increased continuously. This rise in the prevalence rate for autism ASD among eight (8) year old equates to about 20% from 2000 to 2012 and 23% from 2008 to 2012. If the prevalence estimates (1 in 68) for 8 year olds in 2012 is representative for six (6)-seventeen (17) year olds in 2012, we can say that the rise is 23% from 2012 (1 in 68) to 2014 (1 in 45) (Ozerk, 2016).

The researcher is aware that much research has not been conducted in Jamaica, hence the necessity of this research to add to the little literature that is available in Jamaica. Although, the prevalence of autism is mentioned of that in the United States of America, Jamaica is also likely to have significant increase in autism. In relation to the Jamaica Autism Support Association, Wilson (2011) cited in an article that Chang stated that 'the group started with about five parents with autistic children who would meet up to share some of their challenges in raising their children. The group now consists of over 100 parents, caregivers, and professionals who meet every last Saturday at the YMCA to encourage and support each other.'

Responses to the research questions revealed the need of intervention by the Jamaican Government to support families that are affected by autism. All three interviewees stated how emotionally unstable they became when they realized that their children were diagnosed with autism. This is clear evidence of the need for counseling. A support programme should be established at these testing institutions, clinics, or hospitals to refer parents. As it relates to autism, assessment and identification of the problem are worthless without appropriate and consistent intervention. According to Autism Speaks (2017) Autism Spectrum Disorder ASD, refers to a range of 'conditions characterized by challenges with social skills, repetitive

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behaviours, speech and nonverbal communication, as well as by unique strength and differences.’ Therefore, it is necessary continuous for interventions develop social skills and verbal communication of children born with autism.

The Ministry of Labour and Social Security (2006) opines that the ‘Early Stimulation Programme is an extension of the Jamaica Council for Persons with Disabilities that provides an assessment and early intervention programme for children with disabilities from birth to six (6) years old. The researcher questions the period beyond six (6) years old. The child diagnosed with autism suffers from autism beyond six (6) years old. Thus, the financial challenges that the parents encounter to care for their children diagnosed with autism. It is imperative that the Jamaican Government build schools to cater to the needs of these children and also support those institutions that are already established. Early intervention is a preventative measure to build any society.

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