

Autism and Its Impact on Family Dynamics
What Is the Impact of Raising A Child Who Is Nonverbal With Autism Spectrum Disorder
On Family Dynamics?

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Abstract

Background: Families who have an autistic child who is nonverbal experience a tremendous impact on both the parents and on the other children in the family. High levels of stress come within families such as financial stress, mental stress, and emotional stress. It also is a big reward when an autistic child starts to evolve in little aspects of life, so it really makes the stress and sacrifices all worth it at the end.

Objective: The purpose of this research paper is to explore how having an autistic child and nonverbal impact families, siblings, and their daily routines.

Design of Method: Studies have been done to examine how crucial it is that families stick together and communicate with one another to accommodate a nonverbal autistic child. In this review four main points will be discussed: the impact on families with a nonverbal autistic child, the impact on the siblings with a nonverbal sibling, repetitive motions that autistic children exhibit and how the resilience of families helps to have a more successful experience.

Results: The implication of this study is that raising a child that is autistic and nonverbal does come with many hardships but with those hardships come a big reward. Families learn how to function together as one to accommodate the child who is autistic.

Conclusion: Families who have a child who has ASD and is nonverbal, demonstrate how family bonds grow closer which then makes life easier for both the child and families. It is of essence that families seek help when needed and help one another.

Keywords: Autism, misconceptions of autism, impacts on parents, impacts on families, routines in autistic children.

Chapter 1 Introduction

In the United States, approximately 1 in 54 children is diagnosed with autism spectrum disorder (ASD), according to data compiled by the Centers for Disease Control ([CDC], 2020). There has been an increase of ASD diagnosis because of better detection, awareness, and intervention services.

An individual with autism spectrum disorder may have repetitive motions and behaviors such as rocking back and forth, flicking fingers in front of their eyes, and physically moving objects such as opening and closing doors. ASD is a disorder that affects social and communication skills in an individual. People with ASD may not look different from their neurotypical counterparts. A person with ASD can range from gifted to severely challenged. People with ASD may be able to function independently daily; other ASDs need a lot of intervention and assistance with daily life.

According to the National Institute of Mental Health ([NIH], 2020), ASD is known as a “spectrum” disorder because there is a wide range in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. An autistic child’s symptoms may manifest themselves in the severe range. This child may exhibit repetitive motions such as banging their heads against their knees or even banging their heads against the wall. This is one of the factors that Hartmann (2012) explores in her article, *Autism and its Impact on Families*.

Families must improvise many aspects of their lives to accommodate the autistic family member. For example, autistic children, particularly nonverbal ASD children, cannot be left alone, it is incumbent upon the individuals in the family to plan their schedules together so there is always someone with the autistic child. This could create conflicts among the family members

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especially the siblings of the challenged child. As much as they love their autistic brother or sister, the siblings strive to have their own lives and interests. The siblings demand an equal amount of personal time for themselves and from their parents. In her article, *Autism and its impact on Families*, Hartmann (2012) states that the goal of her research was ‘to empower families whose children have ASD as well as present further knowledge and understanding’ (p.3) Hartmann (2012) illuminates the problems siblings incur when she states “The siblings dream of having a normal playmate or companion is no longer congruent with their past expectations” (p.2) Hartmann (2012). Such insight provides a reason siblings react so strongly to some of the demands put on them by having a sibling with ASD.

Children with ASD have severe sensory problems and these are compounded when the child is also nonverbal because they cannot tell you what is causing their distress. The article, *The Everyday Routines of Families of Children with Autism: Examining The Impact Of Sensory Processing Difficulties On The Family*, Schaaf and Toth-Cohen (2011) examines how the severe sensory issues affect the families of ASD children. “Their findings indicated that sensory behaviors are one factor that limited family participation in work, family and leisure activities” (p.) Cohen (2011) This information has important implications not only for professionals but each family member living with an autistic child.

As a researcher, we choose topics that we want to know more information about and may have experienced. My brother has autism spectrum disorder and he is also nonverbal. He functions as a ten-year-old but is actually nineteen. The dynamics of the family and how an ASD affects the relationships and lives will be my focus for this study. My research question is

RQ1: *What is the impact of raising a child who is nonverbal with autism spectrum disorder on family dynamics?*

Chapter 2 : Literature Review

Misconceptions of Autism

Misconceptions of Autism are common due to lack of education, social media, and parents who listen to non-medical professionals. There are a few misconceptions that are commonly known with ASD such as ASD can't be cured so early intervention would have no benefits, behavioral therapy doesn't work, only systematic children should be screened and autism is a single condition. A 2014 article written by Margot Savoy "*Autism 5 Misconceptions that can Complicate Care*", a misconception that Margot explained "While there is no cure for ASD and it is not considered reversible, there is an array of potential ASD therapies and proven benefits of early intervention." (p.311) Savoy (2014).

The article explained, interventions that were rated an "A -", good-quality patient-oriented evidence were effective, early intensive behavioral therapy, melatonin (sleeping pills), parent mediated early intervention and music therapy. Some intervention options that were rated inconsistent with a B rating-inconsistent or limited-quality patient-oriented evidence, would be acupuncture, atypical antipsychotics, and naltrexone.

Children who are diagnosed on the Autism Spectrum Disorder early help the other children in the family and their parents because early intervention can make a huge beneficial impact on the ASD children with cognitive performance improvements, language skills and behavioral skills. Early intervention is significantly important when being or getting a diagnosis done because the faster you find out then the better help you can receive. Even though there is no cure, early intervention will help put the parents at ease and the child as well, so as a family they can figure out solutions that can be accomplished. Another misconception that Savory (2014) argues is "autism is a single condition" (p. 312) "The new term is meant to highlight the

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continuum of symptoms and frequent variability of presentation among those affected, ranging from mild to more severe impairment. Anyone who was classified under DSM-IV criteria, of course, should continue to have an autism/ASD diagnosis. As with previous definitions, ASD is characterized by communication deficits (e.g., inappropriate responses in conversation, misinterpreted nonverbal interactions, and significant challenges in age-appropriate bonding/friendship development” (Savoy, 2012, p.312).

Since no cure has been found yet, families and individuals need to take advantage of new technologies, therapies, and outside help to help themselves and individuals with autism.

Impact on Parents

The major impact on parents who have a nonverbal child on the autism spectrum is that parents have a completely different outlook on life from those who do not have a nonverbal, autistic child. For example, the affected parents experience exceptional financial, emotional, and mental problems once their child is diagnosed with ASD. Parents can become financially overwhelmed because constant care is needed for an autistic child. In some instances, programs that could benefit their child such as ABA might be too expensive to try or to continue for a long period of time. Just the acceptance of the first diagnosis in itself creates overwhelming emotional and mental stress which becomes a daily part of their lives rather than a short-term family crisis.

The parents can start to feel disappointment or become drained by the everyday tasks required, so nowadays there are organizations and groups to help parents overcome the stress and meeting parents who are going through the same issues may lighten up situations. In a particular article *Autism and its impact on Families*, Hartmann (2012) “ Each family handles the vision of their child differently. Just as the spectrum varies, so does each family’s experience. Upon hearing their child’s diagnosis, one study found that in parents, “52% felt relieved, 43% felt grief

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and loss, 29% felt shock or surprise, and 10% felt self-blame” (Hartmann, 2012, p.7). Families having different reactions are normal; how is a family supposed to react when learning the news that their child has been diagnosed with a condition? It is difficult for parents to find comfort because there's so much worry and concern on a daily basis. Parents have to make modifications with work schedules to accommodate the schedule of the autistic child and to accommodate the schedules of other siblings; it puts a strain on everyone if families don't work together as a group. In her article, Hartmann explains “If one parent has to give up his/her job to help with caretaking, this can be financially stressful as it leaves one parent to support the entire family” (Hartmann, 2012, p.9). The daily living aspect of impact on parent's is that usually one is the main caretaker while the other one provides financially or depending on the financial situation within the home. What can be taken away from this research, is that it is important for parents to communicate within themselves and the child with ASD the way that works for them and always to be open to receiving help for parents and the child.

Impact on Siblings

The impact on siblings when having a sibling that has ASD can become stressful for their personal life and professional life. Some stressors may include, introducing a sibling to peers., taking siblings out in public, and frustration with siblings not being able to communicate. In her article, *Autism and its impact on Families*, Hartmann (2012) says “One stressor for siblings is the embarrassment around peers. In having a sibling with autism, they may say or do things that others find “weird” and/or exhibit aggressive behaviors. A sibling may feel awkward or nervous bringing friends around their brother/sister with the fear of the unknown” (p.11). Hartmann (2012).. It makes sense that a sibling would feel nervous introducing their friends to their ASD sibling because people aren't always very open to understanding someone's condition, or they

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just may not feel comfortable. Taking an ASD sibling out in public can put stress on the caretaker sibling flooding them with worries of a tantrum occurring at the time or people staring at both of you. Another study states “ Finally, the concern over their role in future care giving of the child diagnosed with autism can be stressful for siblings. A study indicated siblings reported significant concern regarding the future of their brother/sister’s autism.” . A sibling may feel obligated to take over for the parents when they are no longer able to care for the child diagnosed with autism” (Hartmann, 2012, p.12).The studies show that the sibling may feel obligated to be responsible for the future care of their siblings, this can bring stress on the individual that will be responsible and can cause stress to others around them. A sibling needs to think about being financially stable and will be able to take care of their sibling with ASD and also their parents.

Repetitive and Restricted behaviors

Repetitive and Restricted behaviors in individuals with ASD are common, the most common motions can include, flickering of hands, rocking back and forth, walking on their toes, etc. In 2012 Marina Sarris published an article “*Behaviors that Puzzle: Repetitive Motions and Obsessive Interests*”. In her research, it is shown that repetitive and restrictive behaviors are shown in toddlers at a young age and these behaviors usually lead to a diagnosis of ASD. Some common behaviors can include flickering and rocking hands but more intensive behaviors can be dangerous for the child because they can hurt themselves, an example would be hitting themselves which can be difficult for families to control sometimes.

Another study of RRB would be schedules, children must have structure and routines in order for days to go smoothly, if something is off it can affect mood or behavior in children with ASD. In the study she explained “Researchers have theorized that sensory problems – unusual

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responses to noise, light, touch, smell or movement – may trigger some RRBs in autism.”(p.2).

Sarris (2012) In the research shown most children with ASD are sensitive to any type of movement, examples would include loud music, lights that flicker, noises that can be sensitive to ears. All of these movements can cause discomfort within children.

In the research some problems with RRB would include the stress that affects overall family dynamics and how the family functions on a daily basis, Brian A. Boyd Ph. D., in the Division of Occupational Science at University of North Carolina at Chapel Hill said “These are behaviors that really disrupt family routines” (Boyd, 2012 p.3). Some families have to stick to a certain routine so tantrums don’t occur to stress the child with ASD, unusual disruptions can consume families so the family has to learn, as a unit, in compromising their schedules to make sure the child is able to function daily. It is important to understand what can be done about RRB behaviors, interventions early, and Applied Behavioral Analysis can be conducted to show early signs of behavior in the doctors can conclude if the child has ASD. Research says there can be ways to improve behaviors of RRB, one research stated that rewarding a child if their schedules change during the day can make life easier on the family and on the child themselves.

In the article by Dr. Brian A. Boyd and two other researchers, they explained that the adult may reinforce and reward positive behaviors, such as paying attention, rather than the RRB. “Some research has even shown that children have fewer repetitive behaviors after jogging.” (p.2) Boyd (2012). Positive reinforcement on children with ASD can help make for a better future. The more they get used to everyday changes slowly will only be a positive reflection into their adult life.

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Routines in autistic children

Routines in autistic children are very crucial for the way a family works functionally together to make sure that the child's needs are put in front of theirs. Routines are meant to keep structure for the child and make sure that their schedule keeps the same on a daily basis. In this article the authors explain in depth that families who care for autistic children must maintain unique factors in how the family dynamic functions when having an autistic child. The article *The Everyday Routines of Families of Children With Autism: Examining The Impact Of Sensory Processing Difficulties On The Family*, Schaaf and Toth-Cohen (2011) explained that "Studies have documented that mothers and fathers of children with autism report more stress and burden than parents of children without disabilities and that parents of children with autism experience greater parenting stress than parents of children with special health care needs other than autism" (Tohen, 2011, p.374). Parents who have autistic children experience more stress because of all the factors they have to think about daily, from when the child wakes up to when the child goes to sleep there has to be particular structure in the family's lives. Children can experience many different behaviors which can include sensory-related behaviors. Some examples of sensory-related behaviors would include, jumping on trampolines, or touching, feeling certain objects that can result in these types of behaviors. The study included some impacts that would take place both inside the home and outside the home.

The study showed routines for children and how difficult it is to keep up a routine at home but as well it is very important, in the study " Children with sensory issues often experience meltdowns during this time due to the multitude of stimulation that takes place during the morning routine, as well as the time demands that usually accompany these routines, and such was the case for our sample" (Tohen, 2011. p.381). In the morning it may be most difficult

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because the child wakes up and you want to be able to keep calm and form the structure from the first waking up. The way the family starts the day with the child will put into place what kind of day the child and the family have. It also puts stress on the parents and siblings because if the child doesn't get up on his own or maybe has a meltdown this leads to parents being late for work and siblings maybe late to school. Another example would be dinner time for the family, most autistic children have issues eating the same food that their families would eat, so this can cause stress because now families have to work around the child's sensory issues of how the food looks to how it feels. Another sensory behavior would be for a child to sit at the dinner table which most families had problems with in this study that a child can't sit at the dinner table for more than ten minutes.

The article explained how routines outside the home impact the family and the other children. It explores how difficult it can be when they go out to stores, on vacations, to appointments, on plane rides and on car rides. All these events can be stressful for the child due to their sensitivity to hearing or touch. In the study "Children with sensory sensitivities are oftentimes unable to manage challenges such as these, as they experience an inability to regulate sensory information and respond in adaptive ways." (Tohen, 2011, p.382)). These outings when families decide to go out with the child leaves them a lot to think about. Will my child have a meltdown? Will my child be sensitive to the lights or sounds?

Before leaving the house, parents repeat the questions mentioned previous in their head over and over when leaving the house with their child. It really puts into perspective how difficult it can be, but, at the same time, parents get used to this routine and they schedule so it becomes the new normal. Sometimes parents can't take their kids to certain events due to such difficulties. Though difficulties come when having an autistic child and their routines, it is

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important to remember for parents to be patient with the child and to remember to take a step back and look how far the child has come from inside the home to the outside of home.

Resilience in families of children with ASD

The resilience that families of children with ASD have is incredible. The article “*Evidence of resilience in families of children with autism*, Bayat, M. (2007), explains how families have become closer and have made positive steps forward for the families and children to work together and make life easier in certain aspects. In this study both quantitative and qualitative methodologies were used in order to examine families’ closeness and perseverance in families who have a child that has ASD. The study used a survey methodology. During the last decade family researchers were interested in learning how some families facing adversity managed to function well and come out stronger, while other families who face similar situations do not do as well. Resilience has been described as the ability to withstand hardship and rebound from adversity and ultimately becoming more strengthened and resourceful. Some of the factors they found in the more successful families had a strong family connectedness, positive attitudes toward the child’s disability and “spiritual and personal growth were identified and examined” (citation) Some of the other factors responsible for certain families experiencing success were:

- 1) The child’s warmth and his own resilience.
- 2) The child’s tenacity and perseverance
- 3) The closeness of the family unit and their ability to pull together to manage.
- 4) The assertiveness and skill that the parents developed in caring for the child
- 5) The growth in empathy and kindness in the siblings. (p.710) Bayat (2007). This article examines the success and determination of families that are dealing with a child that has ASD and is nonverbal. Overall in their findings it stated that more families became

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stronger when all working together and that even though there are obstacles along the way it is just how families learn to cope.

Chapter 3: Methods

Phase I: Literature Search

Experts share research to help us understand conclusions in their research findings. I systematically searched for literature to conduct a research study on a subject. A content analysis of the findings will follow in Chapter 4 Results. Sources were found which were reviewed and annotated by the researcher. The literature was found through a search on Google Scholar which provided peer-reviewed articles, scholarly sources, and websites. I wanted to get the best results from experts in the field of autism and autism dynamics on families.

When reviewing my topic, which began as just “autism,” I realized the topic was too broad and my thoughts were more about the development of autism. I contacted the Purchase College Librarian to help gather articles about the development of autism. I submitted a first draft to my professor and then we both agreed that I should narrow my initial topic.

I found some articles within the topic and then something struck me and I decided to go with the impact of autism on families when dealing with a nonverbal autistic child/sibling. The exploration of information included the online data library databases, at Purchase College, State University of New York in Purchase, New York.

I wanted to minimize the results so that I would find the articles that were specific to my topic. The database, PsycArticles was helpful when I used keywords. The key words used were *autism, nonverbal, impacts, parents, and siblings*. Those few words helped me throughout the research search. Next, I conducted a search using Google, and under the search entering keywords like *repetitive and restrictive behaviors, effects on families, effects on siblings, impacts on families, and lastly, impacts on siblings*. The result was literature that provided me with research from experts and their predictions on the topic of what the impacts of raising a child

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who is nonverbal with autism spectrum disorder on family dynamics. The literature research will answer the research questions:

RQ: What is the impact of raising a child who is non-verbal with autism spectrum disorder on family dynamics?

Phase II: Conversations with Participants

My strategy for conversations with participants was to ask semi-structured questions that helped to gather primary source data. The conversation questions asked went into more depth to glean more data about how participants feel on this certain subject. These questions were asked because participants can answer on a personal level and speak about their ups and downs when having someone who is autistic and nonverbal in the family.

Participant conversations were held on an individual basis with parents and siblings who have someone in their family who is a nonverbal autistic child. A total of eight participants were chosen. The breakdown of the participants was four of the participants have siblings with autism and four are parents of children with autism. All participants live in Westchester, a suburb 25 miles outside of New York City. Using adapted survey research during conversations gave me an opportunity to see if both siblings and parents felt the same impacts daily. The conversations gave me an opportunity to see how participants felt about impacts and coping when it came to raising an autistic child who is nonverbal. The conversations were very beneficial and provided an understanding and insight into the research question.

Participants were asked the same following questions.

Q1- *When you learned that your child/sibling was diagnosed with autism, what was your first reaction?*

Q2 - *Do you feel that having someone who is nonverbal and autistic in your family impacts you as an individual?*

Q3- *What are some of the ways you cope with having someone who is nonverbal autistic in your family?*

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Q4- *What are some stresses and challenges of living with someone who is autistic and nonverbal?*

Q5- *Did the relationship between you and your other children change or did relationships and you and your parents' relationship change in a positive or negative way?*

Q6- *Do you get "looks" when going out in public with your sibling/child ?*

Q7- *What makes it all worth it at the end of the day?*

Chapter 4: Results

Doing this survey helped me understand the feelings and impacts siblings and parents go through when having someone in the family has autism and is non-verbal. I have received many of the same and many different opinions when asking participants questions. I have devised seven questions where eight participants are given questions and they answer in how they feel comfortable. Their feedback was given and then I grouped them within tables. The answers that were given are answers that I was looking for towards the impacts on families when having a child with autism. Growing up with someone who is autistic and nonverbal really puts into perspective what life is. My brother taught me to never give up and keep pushing through no matter what route life takes you, everything will fall into place like a puzzle piece. Even though hardships will come every day is a new day and knowing that I have a brother like Jan makes me push harder and help people around me. It taught me patience as well as appreciation. Small milestones to other people are huge to me and my family as well as many other families who have an individual with autism. There is no greater accomplishment in life than being a sibling to someone who has autism and is also nonverbal.

In Table 1 participants were asked what was their reaction when first finding out about their child or sibling diagnosis. Participants 1,2,5 and 8 who were the parents were all shocked but felt relieved. Participants 3,4,6 and 7 all stated that there was depression or anxiety but it put life into perspective.

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Table 1		
<i>Q1: When you learned that your child/sibling was diagnosed with autism, what was your first reaction?</i>		
<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Shocked and confused-honestly the news was hard on me as a parent.
2	Parent	Relieved because we have been searching for a diagnosis for two years.
3	Sibling	Anxiety, stress.
4	Sibling	Depression.
5	Parent	Relieved.
6	Sibling	I was relieved because we, as a family, finally knew that our brother has been diagnosed with autism. It was a blessing in disguise.
7	Sibling	First reaction was I was obviously shocked and then put myself back into reality that this is really happening.
8	Parent	I counted my lucky stars because it could have been way worse.

In Table 2 participants were asked if having someone in your family impacts you as an individual. Participants 1,2,5 and 8 all said that it made them a better person and taught them to find themselves again. Participants 3,4,6 and 7 stated that it opened their eyes and made them grow.

Table 2

Q2: Do you feel that having someone who is nonverbal and autistic in your family impacts you as an individual?

<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Yes, it makes me better as a person
2	Parent	Yes, the comeback is always greater than the setback
3	Sibling	Yes, absolutely it opened my eyes to being more patient.
4	Sibling	Yes, it taught me a life lived for others is a life worthwhile.
5	Parent	Yes, it impacted me in my growth as an individual and as a parent
6	Sibling	Yes, the impacts have been positive because I use lemons to make lemonade.
7	Sibling	Yes, as a sibling it taught me that family dynamics are important so as an individual it really makes a point on how you're impacted.
8	Parent	Impact isn't even the word this child made me into a better person on a daily basis. I wake up and I say to myself what change can I make today. What can I do better to make his life easier?

In Table 3 participants were asked what are some coping mechanisms that families have. Participants all cope with different ways like meditating, walks, work, and therapy.

Table 3

Q3: *What are some of the ways you cope with having someone who is nonverbal autistic in your family?*

<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Coping for me is reading a book at night when everyone falls asleep.
2	Parent	Waking up and starting the day of f with a run around the neighborhood.
3	Sibling	Nature always really spoke to me so when I'm under some stress I'll go for a hike.
4	Sibling	I cope by going to therapy.
5	Parent	Coping to me is when I meditate.
6	Sibling	Making time for myself is important so I know I can fully put myself in when the day starts.
7	Sibling	Once a week my family and I sit down and talk about any issues we may have had during the week and to resolve them.
8	Parent	I tend to cope by going into work and when I'm at work it makes me focus on work. I make sure to separate my home from my work.

In Table 4 participants were asked some of the challenges and stresses of living with someone who has ASD. Most participants were worried about tantrums in public or Participant 2 stated that lack of sleep can cause children not to go to school.

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Table 4

Q4: What are some stresses and challenges of living with someone who is autistic and nonverbal?

<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Stressor would be if my son would be having a tantrum in public and I can't do anything about it.
2	Parent	A stressor would be when my son doesn't go to sleep because he has no school.
3	Sibling	I would say the top stressor is introducing someone to my sibling.
4	Sibling	Challenges would include a normal schedule, if there is no school my brother's routine is off.
5	Parent	A stressor or challenge would include financially being able to take care of my son.
6	Sibling	Inviting a friend over and they don't know your sibling is nonverbal,
7	Sibling	A challenge would be when I try to work with my sibling on his cards from his school that he takes home and I start getting impatient.
8	Parent	A stressor would be feeling mentally and physically draining at times.

In Table 5 participants were asked about if relationships changed in a positive or negative way, parents mostly agreed that relationships became stronger over time even though it is difficult. Participants 4 and 5 understand why parents have to give more attention to the child with ASD and Participants 5 stated that their parents gave them a good life so they cannot complain.

Table 5

Q5: Did the relationship between you and your other children change or did relationships and you and your parents' relationship change in a positive or negative way?

<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	As a parent I try to show everyone the same affection but it is difficult
2	Parent	As a parent, I can say that my other children and I have a stronger relationship than before.
3	Sibling	As a sibling I would say it's bitter sweet, my parents need to show more affection toward my sibling who has autism more than me and I'm okay with it as I get older.
4	Sibling	Speaking from a sibling's side I feel like my parents often do see that one child gets more attention but they understand why.
5	Sibling	I would say that my parents work very hard to give us a good life so I can't complain.
6	Parent	My kids know I love them all so I try to do the best I can and I think they know that.
7	Sibling	Positive never negative we can only build up in relationships between one another.
8	Sibling	As a sibling I try to make the best out of everything so I would say positive because we all work together.

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In Table 6 most participants agreed that even though they do get “looks” they tend to ignore them now. Participant 6 explained that they aren’t in their shoes so let them keep looking or Participant 7 explained that they had to get over the looks because you can’t control other people.

Table 6		
<i>Q6: Do you get “looks” when going out in public with your sibling/child ?</i>		
<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Yes, we get looks and I learned not to let that affect me.
2	Parent	Absolutely, everywhere we go from supermarkets to the gym someone always stares.
3	Sibling	Yes, and it gets really annoying after a while.
4	Sibling	I tend to ignore it so I don’t see “looks” anymore.
5	Parent	Yes, I think people need to mind their own business.
6	Sibling	Let them keep looking because they aren’t in my shoes.
7	Sibling	I happened to get over that real quick because you can’t control other people
8	Parent	As a parent it does hurt when I get looks but there's nothing I can do about it so I do the best I can.

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In Table 7, participants were asked what makes it worth it at the end of the day, both parents and siblings agreed that their sibling or child makes it worth it, those little steps throughout time make it all worth it. The improvements that the child made was worth it speaking from Participants 2, 3, and 4.

<u>Participants</u>	<u>Family Relationship</u>	<u>Responses</u>
1	Parent	Looking into my child's eyes and knowing that I did everything possible to create a better life for him.
2	Parent	Seeing my child's improvement in school and at home.
3	Sibling	My brother makes it all worth it, by seeing him smile I know, as a sibling, I did what I could.
4	Sibling	Looking at my brother makes it all worth it because it made me the person I am today
5	Parent	Is it worth it? Every minute of every day I'm blessed to have a son like him. So my answer is yes.
6	Sibling	Watching my brother grow and improve over the years is all I ever need in my life
7	Sibling	He made it all possible. We just guided him 10000x yes it is worth it.
8	Parent	I wouldn't have it any other way.

Chapter 5: Discussion

The basis of this study was to explore how our families operate daily when having a child that is autistic and non-verbal. On a daily basis families have to have certain routines in place from the moment they wake up to the moment they go to sleep. It is important to realize that when families work together it is incredible what they can achieve when accommodating a child who is autistic. Hardships and failure come with dealing with this type of situation; it is of significance that families learn how to communicate with each other to have healthy dynamics. There are misconceptions about autism; it is best if families listen to science and become open to different ideas when it comes to their children as in therapies, school, eating choices, etc. It is important parents seek help when needed because many communities have help online, therapies or in-person meetings with other parents.

On a daily basis, families have many aspects to be concerned about such as structure, schedules, the emotional and mental well-being of the parents as well as that of the other children in the family. Growing up with someone who is autistic and nonverbal really puts into perspective what life is. My brother taught me to never give up and keep pushing through no matter what route life takes you, everything will fall into place like a puzzle piece. Even though hardships will come every day is a new day and knowing that I have a brother like Jan makes me push harder and help people around me. It taught me patience as well as appreciation. Small milestones to other people are huge to me and my family as well as many other families who have an individual with autism. There is no greater accomplishment in life than being a sibling to someone who has autism and is also nonverbal.

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I now feel that little things don't matter that it's the big picture that counts. As Albert Einstein quoted “ *A life lived for others is a life worthwhile.*” The quote puts out what you put in, when dealing with someone that is nonverbal and autistic, you seem to put the child in front of you on a daily basis but it is worth the outcome.

So, What! - Future Research

Families that have a child that has ASD and is nonverbal are incredible in what they can achieve together. Even though there are hardships, struggles and challenges within the home and outside the home, families over the years learn how to cope and be direct with the situation. In the future there should be more organizations and agencies willing to help families overcome certain situations. It is important that the families work together in making schedules and routines for the child that has ASD. Once that happens even though life doesn't get easier it is more efficient when families know when and what should be done. It is important that future research shows both the positive and the negative when having a child that has ASD.

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