Impact Autism Spectrum Disorders Has On Parents

by

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Abstract

The purpose of this study is to determine what kind of impact the diagnosis of ASD can have on parents and what can be done to decrease the amount of stress these parents experience. This study focused on the impact ASD has on parents, specifically, emotions parents experience and factors that cause stress within a family directly impacted by ASD. Through parent interviews, it was evident ASD added stress to the families. It is the parent's ultimate decision on what they consider is a comfortable means of coping. From the parent interviews, it was apparent there was a need for some sort of coping strategies. There was a consensus that parents would like to talk to others who have experience in ASD – whether it is professionally or personally.

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Chapter I: Introduction

In an ideal world, all families would be stress-free no matter what circumstances may get in the way. However, many families with children who have autism spectrum disorder (ASD) become more stressed than families with typically developing children. An article by Baker-Ericzen, Brookman-Frazee and Stahmer (2005, p. 194) supports this statement, "Both mothers and fathers of children ASD report significantly elevated levels of both child and parent related stress in comparison with parents of typically developing toddlers."

In order to understand the content of this study, one must first understand what autism spectrum disorder is. Autism spectrum disorder (ASD) is a broad term used to describe autism and four other disabilities that affect one's ability to socialize, communicate and respond to one's environment, and is typically diagnosed before the age of three (Willis, 2006). Autism is referred to as a spectrum disorder because children can have a wide range of symptoms or characteristics that affect them that range from mild to severe (Willis, 2006). Some of these characteristics include: a delay in communication and social interaction, obsessions over specific objects, repetitive body movements, and having specific routines and rituals which they have to obsessively follow (Willis, 2006). ASD tends to affect males more than females. Currently, Autismspeaks.org (2010) reported that one in every 110 children is diagnosed with ASD and one in every 70 boys is diagnosed. At this time, there are no known cures for ASD. However, there are many treatments which may help lessen the severity of it.

When people think about ASD, most people think about the child who is affected by it. They may think about these children from that specific child's point of view and how they are perceived by others or what it would be like to not communicate effectively with others. Does anyone think about the parents of these children? The parents of children with ASD are often overlooked because everyone is focused on making the child "better." An article by McHugh, Osborne, Reed, and Saunders (2008, p. 1092) stated that, "levels of stress experienced by the parents of children with ASD are enormously high, compared to those experienced by parents of children with almost any other type of disability or health problem."

Parents of children with ASD often go through an emotional rollercoaster after learning the initial diagnosis. Parents go from thinking their child is perfect, to having an incurable disorder that will affect nearly every aspect of their child's life. An expert in the field of autism (Pullen, 2009, p. 14) stated that, "many parents of children with autism have trouble coping with their own personal needs, let alone the many needs of their child with autism." After the initial diagnosis of ASD, parents must learn how to cope with all the changes that are occurring within their family. Parents may struggle getting through daily routines and may need to make personal sacrifices while balancing a family life, spousal relationships, and job. All of those changes can be stressful for one person to handle. There is evidence that a child with ASD can stress the marital relationship and decrease marital satisfaction (Rivers & Stoneman, 2003).

The term "stress proliferation" has been used to describe the impact ASD has on a family, particularly the stress felt by the parents. Benson (2006), a professional in the field of ASD states: "Stress proliferation [is a process that] occurs when an initial stressor or set of stressors in one domain of life engenders additional stressors in other life domains"(p. 686). He also states, "Because stressors in one area of life have the power to negatively affect the activities, roles, and relationships in other spheres to which they are directly and indirectly linked, new sources of stress may be created" (Benson, p. 686). To apply this process to a family affected by ASD is like saying the family is in a downward spiral. Consider the following scenario as a way to clarify the meaning of stress proliferation.

The parents of three-year old Alexander have just heard that he has been diagnosed with ASD – this would be the initial stressor. After going through the initial shock of hearing their son's diagnosis, Alexander's parents immediately began looking for ways to make him "normal." First, they made a decision as to which early intervention program they want him to begin which added more stress because they wanted nothing but the best for their son. Early intervention programs are services provided to children with disabilities to help in the development of language, motor skills, and socialization. This case the early intervention program would help lessen Alexander's symptoms of ASD. Because Alexander had become very dependent on adults around him, his parents decided one of them should quit their job to stay home with him. This decision led to a decrease in their family income. At the same time, their family budget had just begun getting a little tighter due to the added cost of some of Alexander's ASD treatments. Having monetary issues is an additional stressor which led to marital distress between Alexander's parents. The addition of marital stress was another stressor added to the family. In this scenario of stress proliferation, you can see how Alexander's diagnosis of ASD led to several other stress causing factors for his family.

Reducing the amount of stress parents experience when they have a child with ASD is important to ensure a healthy family environment. Before additional research can be done, existing research must first be acknowledged. With the existing knowledge learned, parents of children with ASD can be questioned to learn how their child's diagnosis of ASD has impacted their lives. Through the interview process, parents will share information about their child's diagnosis, their emotions, what caused them stress and the ways they are coping with the stress. From this information, we will be able to examine and share ways to help these parents cope and determine helpful ways in which they can reduce the amount of stress they have experienced.

Because ASD is being diagnosed more frequently, parents need to be aware of what resources are available to them. When given appropriate resources, parents should be able to handle the diagnosis of ASD in a more effective and positive way. Special education professionals and health care professionals who have specialized in ASD should serve as a vital support system for these families. They should provide ways for parents to cope with stress while respecting their time and space. Support group information should be shared with parents so they have a chance to hear other families going through similar experiences and relate to them. The society we live in should also be taken into consideration when thinking of solutions to help these families that have a child with ASD. "When a child is diagnosed with a disability, you would expect society to rush in and help. But that doesn't happen," (Koegel & LaZebnik, 2004, p. 15). There should be more people willing to learn about ASD and accept it for what it is. Along with this, people should spread awareness and advocate for ASD services to show families affected by ASD their support and acceptance.

By taking advantage of the provided help, families of children with ASD will feel the support they need from their doctors, teachers, and the rest of the society so their whole family can be brought up in a healthy, loving and caring household. Using the information from existing research and parent surveys will make it clearer as to what kind of support families are looking for and need.

Statement of the Problem

Parents who have children with ASD often become stressed due to the many factors associated with the complex disorder. Parents need to be offered better, healthier ways to cope and diminish the added stress that ASD brings to their family. The society in which we live needs to become more accepting of ASD; the negative perception some people have about ASD can directly affect families that have a child with ASD.

Purpose of the Study

The purpose of this study is to determine what kind of impact the diagnosis of ASD can have on parents and what can be done to decrease the amount of stress these parents experience. This study will focus on the impact ASD has on parents, specifically, emotions parents experience and factors that cause stress within a family directly impacted by ASD. The current research available will be examined as well as interviews of parents in western Wisconsin who have a child with ASD. The interviews will be completed in the summer of 2010. From the data that is collected, more knowledge will be obtained about how parents are impacted by ASD and in return, it will be clearer as to what kind of support these parents want and need.

Research Questions

The three questions this study will attempt to answer are as follows:

1. What are the causes of stress for parents with children who have ASD?
2. How does stress from the diagnosis of ASD impact parents?
3. What do these parents feel the society can do to support them more effectively?

Assumptions of the Study

This study included the following assumptions: a) all parents with a child who has ASD experience some stress at one point; and b) the age of the child when diagnosed with ASD is associated with the amount of stress felt by parents.

Definition of Terms

The following terms have been defined to enhance the knowledge of the readers and to provide them with a better understanding of this study.

Asperger's Syndrome: A form of autism spectrum disorder in which children have difficulty with coordination, vocal tone, depression, violent reactions to change, and have a tendency for ritualistic behavior, but unlike other forms of ASD, these children learn how to socialize and communicate as they become adolescents (Willis, 2006).

Autism: A form of autism spectrum disorder in which a person demonstrates either delayed or atypical behaviors in at least one of the three categories: interaction, communication, or behavior and is typically diagnosed before the age of three (Willis, 2006).

Autism spectrum disorder (ASD): A broad term which is used to describe autism and four other disabilities that affects one's ability to socialize, communicate, and respond to one's environment (Willis, 2006).

Childhood Disintegrative Disorder: A degenerative form of autism spectrum disorder in which a child develops normally, but loses the ability or seems to forget how to do things that he or she once mastered (Willis, 2006).

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS): A form of autism spectrum disorder in which a child has autism, but the characteristics displayed by the child are not like those of children with autism and usually is diagnosed after the age of three (Willis, 2006).

Rett's Disorder or Rett's Syndrome: A degenerative form of autism spectrum disorder which is more common in girls (Willis, 2006).

Stress: An emotional factor that causes bodily or mental tension resulting from factors that tend to alter an existent equilibrium (Merriam-Webster, n.d.).

Stress proliferation: A process that occurs when an initial stressor or set of stressors in one domain of life engenders additional stressors in other life domains (Benson, 2006).

Limitations of the Study

A limitation to this study could be the lack of family input from the western Wisconsin region. In order for the data to be consistent, the researcher would like to choose families that have similar characteristics. These characteristics include having a similar family structure and of ASD diagnosis. The children with autism in the families should be around the same age and have a similar diagnosis of ASD.

Chapter II: Literature Review

Introduction

This chapter is a review of the research and literature that relates to stress and the impacts it has on parents of children diagnosed with autism spectrum disorder (ASD). The topics in this literature review include: information about ASD to further the reader's knowledge about what ASD is and how prevalent it is becoming amongst today's children, the emotional effects the diagnosis of ASD has on parents, and information about how stress affects parents.

Autism Spectrum Disorder (ASD)

Autism spectrum disorder can be described as a complex developmental disorder that affects one's ability to socialize, communicate, and respond to his or her environment and is typically diagnosed before the age of three (Willis, 2006). Benson (2006, p. 685) states, "One of the most severe disabilities affecting young children is autism, a disorder that adversely affects nearly every aspect of the child's development." The word autism was first used by Leo Kanner to describe a group of children he was observing (Koegel & LaZebnik, 2004). The word autism means "alone" and the group of children Kanner had observed had a preference to be alone (Koegel & LaZebnik, 2004). The words "spectrum disorder" have been added onto the term "autism" because children can have a wide range of symptoms or characteristics that affect them that range from mild to severe (Willis, 2006). A parent of a child with ASD and author (Notbohm, 2005, p. xix), stated that, "No two children with autism will be completely alike. Every child will be at a different point on the spectrum."

Characteristics of autism spectrum disorder. There are many different characteristics that can be used to describe how ASD affects children. Some of these characteristics include: a delay in communication and social interaction, obsessions over specific objects, repetitive body movements, and having specific routines and rituals which they obsessively follow throughout their day (Willis, 2006). More specifically, the *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders* (2000) stated that an individual must meet at least six of the developmental and behavioral characteristics from the list before the age of three with no evidence for other conditions that are similar. This list of diagnostic criteria includes three broad developmental and behavioral areas including 1) impairments in social interaction; 2) impairments in communication; and 3) restricted repetitive and stereotyped patterns of behavior, interests and activities. Each area includes specific criteria pertinent to the area. A more comprehensive list can be found in Appendix A.

When diagnosing a child who shows characteristics of this complex disorder, one must decide to what extent the specific ASD characteristic affects the child so they can determine where he or she falls on the spectrum (Koegel & LaZebnik, 2004). The diverse characteristics of ASD may have profound effects on the parents of children with ASD. "Parents and clinicians agreed that communication impairment, uneven cognitive abilities, and problems in social relations were the autism-related symptoms that were most stressful for mothers and fathers of school-aged children" (Carter & Davis, 2008, p. 1279). In a similar article, Botts, Hoffman, Hodge, Lopez-Wagner, Nam and Sweeney (2008, p. 155) state, "Behavioral symptoms associated with children's autism including their language and communication difficulties, cognitive impairments, reactivity to frustration, and repetitive, self-stimulatory behavior, have been found to be related to parents' stress."

Types of autism spectrum disorder. Autism spectrum disorder is a very complex disorder not just because of the many characteristics that define it, but also because there are five types. The five types are: Autism, Pervasive Developmental Disorder Not Otherwise Specified

(PDDNOS), Asperger's Syndrome, Rett's Syndrome, and Child Disintegrative Disorder (Heller's Syndrome). The diagnosis of PDDNOS is given when a child is over the age of three and has been diagnosed with ASD even though he/she does not show characteristics like other children with ASD (Willis, 2006). Willis (2006) stated that PDDNOS is the most confusing type of ASD to comprehend because of its broad definition. A child with Asperger's Syndrome differs from a child with ASD because a child with Asperger's Syndrome becomes more social and communicative as he or she grows into an adolescent (Willis, 2006). Rett's Syndrome is different from ASD because it affects females more than males and it is considered a degenerative disability, which means their condition will worsen as they grow older (Willis, 2006). Childhood Disintegrative Disorder or Heller's Syndrome is also a degenerative condition in which children seem to forget how to do things they once mastered such as talking or toilet training (Willis, 2006). Willis (2006, p. 18) compared the various types of ASD to a tree, "each branch, though slightly different from the other branches, is still part of the tree."

Treatment of autism spectrum disorder. Currently, Autismspeaks.org (2010) reported that there is no cure for ASD. However, there are many treatment options for children with ASD that lessen the severity of their symptoms. Early intervention treatment services can significantly improve a child's development. An early intervention treatment can help children from birth to three years old learn important skills that they may not be able to learn on their own.

Two examples of treatment options include The Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) and Applied Behavioral Analysis (ABA). The Treatment and Education of Autistic and related Communication-handicapped Children is the best-known model for special day classes for children with ASD (Siegel, 2008). According to Siegel (2008, p. 160), "TEACCH focuses on improving adaptive and independent living skills by modifying the environment to accommodate the characteristics of those with autism disorders."

Another option to help children with ASD is Applied Behavioral Analysis (ABA), which is also known as the Lovass Model. This method is highly structured and works on targeted skills and behaviors based on the children's needs (Autismspeaks.org, 2010). Autismspeaks.org (2010, ¶ 5) describes this method in greater detail, "Each skill is broken down into small steps and taught using prompts which are gradually eliminated as the steps are mastered." The Autism Speaks website also says ABA principles and techniques have helped many people with ASD live happy and productive lives (Autismspeaks.org, 2010). Davis, Rosswurm and Zane (2008, p. 45) also state, "Applied Behavioral Analysis has been shown to produce substantial benefits for many children with autism."

Prevalence of autism spectrum disorder. Autism spectrum disorder is becoming more prevalent across the United States. At the beginning of 2009, Autismspeaks.org (2009) stated that the probability of a child having ASD was one in every 150. There have been many news sources reporting a new statistic about the prevalence of ASD. The most recent statistic on the Autism Speaks website states, "Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common that childhood cancer, juvenile diabetes and pediatric AIDS combined" (Autismspeaks.org, 2010). Because ASD is more common in boys, the website also states one in every 70 boys is being diagnosed with autism each year (Autismspeaks.org, 2010). This information was backed by the Centers for Disease Control and Prevention (CDC). The CDC released the following statistic to show how prevalent ASD will become within a year's time. "If 4 million children are born in the United States every year, approximately 36,500 children will eventually be diagnosed with a type of ASD" (CDC, 2010).

Emotional Effects the Diagnosis of ASD Has on Parents

After the initial diagnosis of ASD, parents must learn how to cope with all the changes that are occurring within their family. Davis, Rosswurm and Zane (2008, p. 48) found that, "parenting children with developmental disabilities is associated with impaired mental health, higher levels of stress, a sense of devaluation and blame, and impaired physical functioning such as tiredness or exhaustion." Experts on the treatment of autism (Koegel & LaZebnik, 2004, p. 5-6) said, "Over the years, I have talked with thousands of parents of children with autism, and I can tell you that getting the news is horrific, terrifying, stressful and, depressing." After parents hear their child will no longer be developing like a typically developing child, there is no doubt they would experience a great amount of emotion.

Stages of grief. Dr. Elisabeth Kubler-Ross provided pioneering work to understand death, dying, and grief (Gibson, 2004). She then developed the five stages of grief as: denial/shock, anger, bargaining/guilt, depression, and acceptance (Gibson, 2004). Parents often go through their own stages of grief after hearing their child has ASD because it is an unexpected change in their lives. Parents with disabled children present higher levels of dysphoria, intense anger, guilt, depression and anxiety (Davis, Rosswurm & Zane, 2008). People experience the stages of grief differently because there is no sequential order in which each stage should occur and because some people may not experience some of the stages (Gibson, 2004).

Shock/Denial. At first, parents may be shocked and go into denial about their child having ASD. After realizing that their child has the characteristics of ASD, parents may begin making excuses for why their child is not talking or making eye contact. Koegel and LaZebnik (2004, p. 12) stated, "It's very difficult to find out that the child you love so much has a disability, and it's very natural and understandable to hope against hope that the people who have diagnosed him are in error." Hearing the diagnosis can be difficult for parents of children with ASD because they may have felt that there was something wrong with their child and after weeks and months of wondering, they have an answer, an answer they did not want to hear. After the parents hear the diagnosis, they begin to face the reality of life with a child with disabilities and usually are not ready to accept it (Willis, 2006). This is typically when parents begin searching for second opinions about their child's diagnosis. A parent can stay in the stage of denial for months and even years (Koegel & LaZebnik, 2004).

Bargaining/Guilt. Another emotion parents may feel after hearing their child's ASD diagnosis is bargaining or guilt. Parents typically wonder if they did something that caused their child to have ASD and blame themselves for what happened to their child and if they did, what can they do to make their child not have ASD. Mothers are most commonly associated with this stage. "Self-blame is also common, as a parent (usually the mother) feels that she did something wrong during pregnancy that caused the child to have autism" (Willis, 2006, p. 200). Authors Koegel and LaZebnik (2004, p. 14) brought up a well-known theory of the past, "Feelings of guilt have been compounded by early unsubstantiated psychoanalytic theories that suggested that cold, unloving mothers were the cause of autism." They go on to say that scientific research has documented that there is no difference in mothers who have children with ASD as opposed to mothers who have no children with ASD.

Anger. Anger is another emotion parents may experience after hearing about their child's ASD diagnosis. Parents get angry and want answers as to why their child has ASD. This is also when parents may find other things or people to blame as the reason for the child's ASD diagnosis, which causes them to direct their anger at that particular reason (Willis, 2006). The anger parents express may be directed towards their child's doctors or teachers at first because they are usually the ones informing the parents of the diagnosis (Koegel & LaZebnik, 2004). "The additional stress of raising a child with a disability leads to frustration and disappointment for the parents" (Davis, Rosswurm & Zane, 2008, p. 48).

Depression. Parents of children with ASD may also experience depression. In fact, depression is common in parents of children with ASD (Koegel & LaZebnik, 2004). Ericzen, Frazee-Brookman and Stahmer (2005, p. 201) reported that "Mothers of children with autism report higher levels of depression compared to mothers of children without autism." Another author (Benson, 2006, p. 685) states, "One problematic mental health outcome commonly linked to the demands of parenting a child with autism is depression." Benson (2006, p. 693) also states, "The high level of depression suggests parents of children with ASD are at increased risk for poor mental health outcomes, not only because of the demands of caring for their child with ASD, but because of other stressors which may be engendered or exacerbated by their child's disorder."

The length of depression experienced by parents differs from one parent to another. "Nothing is more depressing than uncertainty and inactivity" (Koegel & LaZebnik, 2004, p. 17). Autism spectrum disorder is full of uncertainty – whether or not treatments will work and if they do, when will they begin to show results. When parents become depressed, it is not only detrimental to themselves, but also to their family. "Depression leads to inactivity and withdrawal from society; it will damage you, your marriage, and your children" (Koegel & LaZebnik, 2004, p. 17).

Acceptance. The last stage of grief parents must go through is acceptance. This is usually the last stage parents experience because it takes time for them to come to the realization that their child has ASD. "Ultimately, most families come to accept the disability as being a part of who the child is and learn to appreciate the child for what he can do rather than what he cannot do, (Willis, 2006, p. 201). Though this may be the last stage of grief, it can also be a positive experience for parents to go through. After coming to terms with the diagnosis, parents can put all other emotions behind them and work to better their life and the lives of their children. It may take many years to get to this stage, but will be well worth it in the end.

Stress Experienced by Parents of Children with ASD

Many parents of children with ASD experience stress one way or another. An article by Benson (2006) stated, "Autism's impact on the family appears to be particularly severe, with parents of children with autism frequently reporting high levels of stress associated with their child's social and communicative deficits, problem behaviors, and level of dependency" (p. 685). Mothers and fathers of children with disabilities tend to stress about different things. Mothers tend to stress about providing appropriate care for their child, whereas fathers tend to stress about the financial toll ASD puts on their income (Koegel & LaZebnik, 2004).

In a study by Hevey, Honan and Tehee (2009), the following list of the top sources of stress as reported by parents of children with ASD was compiled:

1. Inappropriate and unpredictable behavior
2. The future
3. Education and learning
4. Personal constraints
5. Child's friendships, interactions with other children
6. Meeting needs of other family members
7. Lack of and/or delay of basic skills
8. Social aspects

9. Attaining support and services/ Speech and language/ Sexuality (equally ranked)
10. Disruption of home life and environment/ Diet/ Understanding children's needs (equally ranked)
11. Finance
12. Transport

Stress proliferation. The term *stress proliferation* has been used to describe the impact ASD has on a family, particularly the stress felt by the parents. "Stress proliferation [is a process that] occurs when an initial stressor or set of stressors in one domain of life engenders additional stressors in other life domains" (Benson, 2006, p. 686). To apply this process to a family affected by ASD is like saying the family is in a downward spiral. For example, the initial stressor in a family with a child with ASD could be the diagnosis, followed by a set of stressors such as monetary issues due to a parent(s) quitting their job to care for their child or marital issues due to less time spent together because more time has been devoted to their child.

Parents with children who have ASD may struggle getting through daily routines and may need to make personal sacrifices, while balancing a family life, spousal relationships and job obligations because their child was affected by ASD. That is a great deal of stress for one person to handle. Pullen (2009) reported that, "Many parents of children with autism have trouble coping with their own personal needs, let alone the many needs of their child with autism" (p. 14). Benson (2006, p. 693) sums up his findings by saying, "Parent well-being can be both directly and indirectly affected by their child's ASD, with stressors expanding and crossing into areas of the parent's life not directly related to their child's autistic disorder."

Stress induced from caring for a child with ASD. Parents of children with ASD, not only have to worry about providing the essentials of caring for their child such as food, clothes, and shelter; they have to learn how to care for a child with a disability. "A number of care-taking responsibilities increase the sources of stress for these parents" (Baker-Ericzen, Brookman-Frazee & Stahmer, 2008, p. 195). A study about stress levels of parents of children with ASD stated there was higher parental stress when their child had higher levels of autism symptoms (Carter & Davis, 2008). Some of the most stressful ASD symptoms may include verbal expressive difficulties, cognitive inconsistencies and behavior problems (Baker-Ericzen, Brookman-Frazee & Stahmer, 2008). A study by Hevey, Honan and Tehee (2009) reported mothers of children with ASD were more burdened with domestic responsibilities and fathers were more focused on providing economic and financial stability when it came to caring for their family.

The time and energy parents devote to find intervention programs for their child with ASD while caring for that child and/or their siblings' places stress on the family (Ericzen, Brookman-Frazee & Stahmer, 2008). In seeking treatment for their child with ASD, parents should be cautious about "fad treatments." Fad treatments are interventions that are backed by celebrities, use scientific jargon to support them, sound logical and are discussed in the media (Davis, Rosswurm & Zane, 2008). Davis, Rosswurm and Zane (2008, p. 46) state, "Fad treatments have no substantial body of research showing they are effective in treating any aspect of autism. Thus, there is little confidence that they are effective in treating any aspect of autism." Davis, Rosswurm and Zane (2008, p. 49) go on to say, "The families are so emotionally invested in doing anything that can help their child; they are likely to try anything." Fad treatments can have negative long term effects. Without any research to report their effectiveness, fad treatments can be a waste of money and time – time that could have been used for a more effective treatment. Fad treatments can also take an emotional toll on parents. Parents will buy into a fad treatment they think is going to make their child's ASD symptoms decrease and in the end, get minimal or no results at all. In the end, parents experience false hope.

Another cause of stress for parents is how to communicate with their child who lacks communication and social skills. "Parents of children with autism need to master a whole new set of parenting skills which adds even more stress to their emotional lives," (Koegel & LaZebnik, 2004, p. 20). Parents must realize their child will have trouble communicating their feelings, but will still be able to show affection in their own way. According to Siegel (2008, p. 88), "If the child wants contact, parents must give it; but, most often, when the child has had enough, she moves off, and the parents need to learn to feel satisfied with that."

Not only do parents have to worry about how to take care of their child in the present; they often worry about the future of their child. "Of all the fears that keep a parent awake at night, concern about her child's future – how well the child will ultimately be able to function in the real world - is probably the biggest one" (Koegel & LaZebnik, 2004, p. 18).

Marital stress on parents. There is evidence that a child with ASD can stress the marital relationship and decrease marital satisfaction (Rivers & Stoneman, 2003). "Parents of children with ASD report more symptoms of anxiety and marital dissatisfaction than parents of children with other types of disabilities" (Bedesem, Boyd & Mancil, 2009, p. 523). After hearing the initial diagnosis, parents will often times play the "blame game" in which parents go back and forth blaming each other for things that they may have done to cause their child's ASD. As stated by Willis (2006, p. 200), "It is during this [anger] phase that marriages end, and, as a result, families may begin to face great difficulty and begin to fall apart."

Another controversial topic that arises is what kind of treatment or intervention can be implemented to benefit the child the most. Agreeing on the best treatment programs for children can cause disagreement between parents (Koegel & LaZebnik, 2004). If one parent devotes his or her time and energy to the child, he or she may be putting their relationship with their significant other on the back burner. This is evident through a statement made by Hevey, Honan and Tehee (2009, p. 35), "Having a child with autism was the best predictor of poor father involvement, highlighting the aggravating effect of autism to the marital relationship." An excerpt from the book, *Special Children, Challenge Parents* describes how one man's son with ASD impacted his marriage.

> Unfortunately, I didn't get any help from within my marriage. I felt the most alone at home. To put it simply and kindly, the strain Tariq's of disability added to our other stress and led to divorce. After years of trying to go through it together, it was easier to try it alone. (Naseef, 2001, p. 7).

From this excerpt, we gain a parent's perspective of how ASD can affect a marriage.

Monetary stress. With the diagnosis of ASD in a family, concerns about family income may arise. If both parents work, they may feel that it would be better for the child if one of them stayed home full-time with the child. The consequence of this would be only having one source of income as opposed to two.

The costs of intervention and treatment programs can be expensive. Parents are then left to answer the stressful question of, "Is spending that much money on a treatment that may or may not work worth it to help my child?" Financial stress most commonly affects the fathers of children with ASD more than it does the mothers (Koegel & LaZebnik, 2004).

Monetary issues also come into play when discussing early intervention. An article about the costs of the caring for a child with ASD reported the cost of lifelong care could be reduced by two thirds with early diagnosis and intervention (Davis, Rosswurm & Zane, 2008). "The average annual cost of an early intensive behavioral intervention program was found to be $33,000 per year with the average duration being three years" (Davis, Rosswurm & Zane, 2008, p.45).

The article by Davis, Rosswurm and Zane also presented the annual costs of three different treatment programs. The first program was called Sensory Integration Therapy (SIT) which uses sensory integration techniques to reduce the results of sensory dysfunction. Annually, this program would cost a family $16,500 (Davis, Rosswurm & Zane, 2008). The second program was called Relationship Development Intervention (RDI). This program is designed for parents to learn techniques on how to decrease their child's ASD symptoms by exposing their child to many social situations which promote social skills. The RDI treatment requires parents to attend many workshops and sessions which may cost them approximately $10,000 per year (Davis, Rosswurm & Zane, 2008). Davis, Rosswurm and Zane (2008) referred to SIT and RDI as fad treatments. However, a more successful autism treatment is Applied Behavior Analysis (ABA) which is expensive to implement. Some ABA treatment programs can cost a family approximately $100,000 a year.

Coping Strategies for Parents of Children with ASD

With all the stress of raising a child with autism, parents need ways to cope. Strategies that may be used by parents to cope may include autism support groups to hear from other parents in similar situations, reaching out for support from family and friends, taking parenting classes to learn ways to help their child grow and learn, or seeking professional help to talk about the changes happening in one's family. A study by Bedesem, Boyd and Mancil (2009) resulted in learning that the following strategies were most effective when coping with stress: social support, family support, religion, parent training, social withdrawal and professional help. A study by Hevey, Honan and Tehee (2009) reported the top facilitators of stress relief for parents included: school staff and services, respite services, family and spouses. From both studies, it is clear that both formal and informal coping strategies are important.

Ultimately, it is the parent's decision on how they choose to deal with the stress of having a child with ASD. "Parents struggling with their own emotional difficulties may have fewer coping resources and feel more stressed by their children's challenging behaviors" (Carter & Davis, 2008, p. 1280). Similarly, no two children with ASD will be the same and no two parents are going to express the same emotions and have the same coping strategies. Hevey, Honan and Tehee (2009, p. 35) stated, "Certain personality traits may be more conducive to adaptive coping than others."

Support groups. Support groups should share successful techniques and stories which allow participants to leave with a positive outlook and new strategies to use with their child and not leave depressed from listening to other parents complaining about their child (Koegel & LaZebnik, 2004). Support groups can be beneficial to some parents because they quickly learn others are going through an experience similar to theirs. However, there may be some downfalls to support groups such as the availability and access to meetings in their area. "Coping strategies are related to the resources to which [parents] have access. Without these resources, parents are vulnerable and more likely to be stressed" (Hevey, Honan & Tehee, 2009, p. 34). Siegel (2008, p. 89) points out another downside, "Parents get competitive in subtle and not so subtle ways about who has the "best" therapist, the "most" hours, or the highest-functioning child. Every child with an autism spectrum disorder is different, and any such comparisons are likely to leave you finding something to feel worse about."

Support from family and friends. Receiving support from family and friends may be the cheapest and most accessible support parents can get. As stated by an expert (Siegel, 2008, p. 88) in the field of autism:

> Reaching out for support from your existing network is really important. Research shows maintaining the fabric of the life you had before diagnosis is more important to your longer-term well-being than forsaking it in favor of life as an autism-only mom or dad.

Support from family and friends is considered to be an effective coping mechanism for dealing with the daily stress of rearing a child with autism (Bedesem, Boyd & Mancil, 2009).

Parenting classes. Some parents find relief by taking classes to help them understand and interact with their child more effectively. "Parent education programs that teach parents naturalistic strategies to increase their child's communication have been shows to result in decrease levels of parent stress and depression" (Baker-Ericzen, Brookman-Frazee & Stahmer, p. 195). Disadvantages that come with parenting classes may include availability and access of classes, paying for the classes or finding time to attend the classes.

Professional help. Willis (2006, p. 14) describes what parents need after hearing their child's ASD diagnosis: "A strong support system that includes specialists such a early interventionists, special education teachers, speech pathologists, and occupational therapists." All the support systems mentioned by Willis are examples of professional help. Having this kind of support can help parents cope by meeting their emotional, practical and informational needs (Hevey, Honan & Tehee, 2009).

Social withdrawal. Although not healthy, some parents choose to distance themselves and their families from the rest of the world. After a study about ways to cope with stress, Bedesem, Boyd and Mancil (2009, p. 524) concluded, "The parents explained it was easier to keep to themselves and avoid embarrassing incidents that results in stares and comments from others." However, the study also revealed social withdrawal temporarily displaces the problem which results in stress later that may be much worse in severity (Bedesem, Boyd & Mancil, 2009).

Conclusion

As the literature suggests, there are many different contributing factors that may make a parent's life more stressful due to their child's diagnosis of ASD. Whether it is about the way they care for the children, the future of their child, marital stress, or monetary stress, it all takes a negative toll on parents. Autism spectrum disorder can become a permanent fixture of a parent's life that can take them on a rollercoaster ride of emotions throughout the rest of their lives.

Chapter III: Methodology

Introduction

The purpose of this study is to determine what kind of impact the diagnosis of ASD for a child can have on parents, what can be done to decrease the amount of stress these parents have and what can be done to offer support to them. This chapter will discuss the procedures and methods used to complete this study. In addition, this chapter will focus on descriptions about selecting the sample and instruments, the process of how the instrument was used, the data collected from the study, as well as limitations to the study.

Selection and Description of the Sample

The focus of this study is on parents of children with ASD in western Wisconsin and how they have responded to their child's diagnosis of ASD. Therefore, the sample used in the study included three parents whom all have a child with ASD and at least one other child. Specifically, three mothers participated in the interviews. Two fathers were present during the interviews, but contributed minimally compared to the mothers. The parents were between the ages of 28 and 40 and had at least two children, one of which has ASD. The ages of the children with ASD and the amount of time that has passed since they had been diagnosed with ASD was taken into consideration. There were no restrictions on the age and gender of the parents chosen for the sample.

The parents who participated in the interview were contacted using a variety of methods. A letter was electronically mailed out to parents who were members of the Chippewa Valley Autism Society during the spring of 2010. A copy of this letter can be found in Appendix B. Two parents responded after the letter was dispersed and only one of the parents was interviewed. Two of the parents were verbally contacted through the interviewer's network of family and friends.

Instrumentation and Data Collection

The instrument used to gather data from the sample for this particular study was a set of interview questions approved by the University of Wisconsin-Stout Institutional Review Board for the Protection of Human Subjects. A copy of interview questions can be found in Appendix C. The interview questions included items such as: general information about the child, the parent's reaction after hearing the initial diagnosis of ASD, if/how ASD has changed the parent's lives, the amount of stress (if any) that was experienced after the diagnosis, and if stress was experienced, methods that were used to cope with the stress. The interview included 38 items.

Prior to the verbal interview, a copy of the interview questions were electronically mailed to the parents. For each interview, the interviewer met each of the parents at a time and location convenient to them. During the interview, the interviewer asked the questions and transcribed what the parents said. No measures of validity or reliability have been documented, since this interview was designed specifically for this study.

Data Analysis

The data collected from the responses the parents gave to the interview questions were analyzed and coded to find similarities and differences. The similarities and differences found amongst the most pertinent interview questions were recorded and can be found in tables within chapter four. The information obtained from the responses helped determine what the major causes of stress were for a parent who has a child with ASD, to what extent the stress affected parents and how parents prefer to cope with the stress.

Limitations

Limitations that may affect the sample selection process may include finding an ample number of willing participants who meet the specified criteria to participate in an interview in the western Wisconsin region. The participants must meet the following criteria: must have at least two children including one child with ASD; the children with ASD in the families should be around the same age and have a similar symptom level of ASD. Limitations that may affect the interview method included the varied way the parents chose to answer the questions and the amount of information they were willing to share for each question.

Chapter IV: Results

Introduction

The purpose of this study is to determine what kind of impact the diagnosis of ASD can have on parents and what can be done to decrease the amount of stress these parents experience. This study focused on the impact ASD has on parents, specifically, emotions parents experience and factors that cause stress within a family directly impacted by ASD. This chapter will display the data that was collected during the parent interviews. Questions along with the parent responses strongly related to the subject matter will be revealed in this chapter. Each pertinent question will be listed under the heading it was put under within the interview. Tables will be used to display parent responses to some questions. For clarification, each family was designated with a different letter to help differentiate between the three families. To protect the identities of the families involved, pseudonyms were used.

Basic Questions

This section of the interview included questions relevant to the sample to give readers a better understanding of the three families that participated in the interview. The responses to question number two in Table 1 show the current ages of the children and the age at which they were diagnosed. Currently the children, all of which are boys, are between the ages of six and eight and were all diagnosed between the ages of two and a half and three years old. Question three shows the number of siblings in each family as well as their ages. Each child with ASD has at least one sibling. Two of the children are the oldest of two children and one child is the third oldest of four children.

Table 1

Basic Questions and Responses from Parent Interview

Question	Parent Response
#2: How old is your child and at what age were they diagnosed with ASD?	A: Ben is currently 8 years old and was diagnosed at 2 years and 7 months. B: Bobby is currently 8 years old and was diagnosed at 3 years. C: Wayne is currently six years old and was diagnosed at 2 years and 6 months.
#3: What are the ages of your other children?	A: Devin-13, Emma-11, Jay-2 B. Tommy-6 C. Tina-4

Diagnosis Questions

Question one of Table 2 shows how all three families noticed their child was not developing typically before the age of two. Each family noticed something different about their child. Ben's parents noticed how he kept falling to one side of his head and took him to see a neurologist to rule out any physical aspects. At an eighteen month check up appointment, Bobby's mother and doctor discussed his nonstop hand movement, how he never made eye contact and how he babbled instead of trying to say any words. Wayne's parents noticed how he was not talking, hand flapped, repeatedly walked around chairs and said "ticka" and "ing" repetitively. After recognizing their child was not developing typically, each family went through two or more doctors before getting an official diagnosis of ASD.

Questions four through nine in Table 2 deal with the emotions the parents experienced right after receiving their child's ASD diagnosis. Question four was about the reaction parents had after hearing their child's diagnosis. Two parents were somewhat relieved to hear the diagnosis for two different reasons. Ben's mother felt relieved because she knew it was not fatal and Bobby's mother was relieved because knowing her child had some kind of disorder gave her a sense of validation. However, Wayne's parents felt shocked to hear that something was wrong with their child. According to the responses to question five, all parents went through some of the stages of grief. All parents experienced shock and anger, whereas not all parents experienced guilt, depression or acceptance. Responses in question six revealed that all of the parents knew nothing or very minimal about ASD prior to their child's diagnosis. Question eight asked parents to recall the worst part of hearing their child's diagnosis. Ben's and Bobby's parents felt the worst part was knowing their sons were not going to have a typical life. Wayne's parents were upset about their child being the only one of 36 grandchildren to have special needs. The thoughts and emotions the parents felt after bringing their child home for the first time after hearing their diagnosis were somewhat similar. The parents of Ben and Wayne felt their son was the same son they always had and nothing was going to change that. Bobby's mother instantly began to research ASD and find ways to help her son.

Table 2

Diagnosis Questions and Responses from Parent Interview

Question	**Parent Response**
#1: When did you realize your child may not be developing typically?	A: 1 year and 3 months. Ben's doctor realized he was not reaching his developmental benchmarks. B: 1 year and 6 months. Bobby's doctor suspected something, but didn't know what. C: Between 1 year and 1 ½ years. Wayne was not talking, began to flap hands & did things repetitively.
#4: What was your reaction to hearing your child's diagnosis?	A: Thankful it was not fatal. B. Gave validation, but sad to know their son would not be normal. C. Shocked.
#5: Did you go through the stages of grief?	A: Yes – shock, guilt, anger, acceptance & depression. B: Yes – shock/ denial, guilt, anger & depression. C: Yes – shock/ denial, anger & acceptance.
#6: Did you know anything about ASD prior to your child's diagnosis?	A: Knew nothing. B: Knew it had something to do with socialization. C: Knew nothing, but had heard about it.

#7: Do you feel anything positive came out of hearing your child's diagnosis?	A: No. B: Yes, felt relief. C: Yes, knew why Wayne acted the way he did.
#8: What was the worst part of hearing your child's diagnosis?	A: Knowing that Ben may not do things that other children would do. B: Knowing he would not have a normal life. C: Knowing their child is one of 36 grandchildren with special needs.
#9: What were your thoughts/emotions when you brought your child home for the first time after their diagnosis?	A: Did not react because Ben was still the same child as he was the day before. B: Became interested in what they can do to help Bobby. C: Wayne is still Wayne.

Life After Diagnosis Questions

After hearing the ASD diagnosis, parents had a lot of work to do to get to their sons the help and support they needed. Question one of Table 3 illustrates how the families had changed after hearing the ASD diagnosis. Ben's parents went the extra mile to communicate and interact with him. It seemed the most change occurred within Bobby's family. His parents began talking to him in a more ASD friendly way by including "first, then" statements. They changed their environment to become less cluttered and safer for Bobby. Wayne's parents paid more attention to his self-stimulation and tried to figure out triggered them before they started.

The second question in Table 3 focused on the siblings. Bobby's older brother is very protective and his older sister tends to be more nurturing with him. According to their mother, she feels Devin and Emma will be more accepting of people with special needs throughout their lives. However, their youngest brother Jay is too young to understand the concept of ASD. Bobby's younger brother is also too young to grasp the concept of ASD. To help Tommy better understand ASD, his mother reads him stories about other families that have children with ASD.

Presently, Tommy just thinks his brother is mean and talks too much. Wayne's younger sister is oblivious to the fact that Wayne has ASD.

After finding out their sons had ASD, the parents had to find appropriate intervention programs for them to participate in. Ben and Wayne were both put into the Birth to 3 programs within their county. Wayne was enrolled in an Early Childhood program.

Table 3

Life After Diagnosis Questions and Responses from Parent Interview

Question	Parent Response
#1: Did your parenting ways change after you learned your child had ASD? If so, how?	A: Yes, they changed the way they interacted with Ben. B: Yes, they changed the way they communicated with Bobby as well as their environment. C: Not really, just looked at ways to handle his self-stims
#2b: How do your other children currently feel about their sibling with ASD?	A: Emma is more nurturing of Ben and Devin is protective of Ben and Jay. Jay is too young to understand. B: Tommy is too young to understand, but feels his brother is mean and talks too much. C: Tina is too young to understand, Wayne is just her brother, she doesn't know anything different.
#5: What was the first kind of treatment your child received?	A: Birth to Three program. B: Eary Childhood program. C: Birth to Three program.

Current Living Situation

Almost all questions about the current living situation of the families were included in Table 4. The first question was how ASD affected the families financially. All three families said the Wisconsin Children's Long-Term Support Waiver have helped tremendously when it came to financing doctor appointments and the different intervention treatments their sons were a part of. However, there were some additional costs that were not covered by the waiver. Ben only eats a limited amount of foods which tend to spoil faster which means more frequent trips to the grocery store. Bobby's parents have spent extra money in order for him to have a therapy room within their home. Each family described their financial situation as having enough to put a roof over their family's head and food on the table. Ben's father co-owns a construction company which requires him to work long hours every day while his mother stays home with the children and does book work for the company. His father's long hours and strenuous work causes a whole new whelm of stress for the family. Bobby's parents both work, but his mother chose to take a lower paying job that allowed her to have more flexibility to care for him. Wayne's parents also work full-time jobs. Question three in Table 4 focuses on how ASD affected the parent's relationship with one another. Ben's mother feels as though there has been separation within the family due to the feeling of Ben being her child and Jay belonging to their father. His mother feels their father does not spend much time with Ben, so he makes it up by spending more time with Jay. Ben's mother feels as though his father does not know how to relate to Ben like he does to their other children. Ben's mother feels she rarely get any alone time with her husband. Because their sons sleep with her in her bed, her husband has to sleep elsewhere in their home. Bobby's mother expressed how finding a caregiver for the boys was impossible due to the complex needs and behaviors of Bobby. The relationship between Wayne's parents has been stressed due to the different viewpoints on how to deal with some of Wayne's challenging behaviors.

Questions five and six in Table 4 focus on how parents were directly affected by their child's diagnosis of ASD. Question five was about how ASD has affected parents mentally, physically and emotionally. Ben's mother said she is constantly seeking ways to make Ben's symptoms milder which requires a lot of thinking outside of the box. Ben's mother often feels frustrated because she feels not many people understand what life is like with Ben and many people are quick to make judgments which takes an emotional toll on her. Physically, keeping up with Ben is exhausting because he is constantly on the go and always needs to be under supervision. Bobby's mother feels as though she has become more sensitive to the special needs community. Because Bobby's mother focuses much of her attention on her sons, she has no time to take care of herself because she feels she has more important priorities. Since Bobby's diagnosis, his mother has gained 70 pounds. Wayne's mother feels she has gone above and beyond to be Wayne's advocate. She has made it her job to pinpoint what upsets Wayne and tries to find a solution to prevent or avoid the situation. She also experiences a lot of stress knowing that Wayne cannot effectively communicate with her like she wished he could.

Question six of this part of the interview asked the parents to identify ways ASD made their life more stressful. Ben's mother described their home as constantly feeling like it is on pins and needles. Everyone is careful not to do anything that may set off Ben. Ben's mother wishes the whole family could sit down and watch a movie together, but with Ben's short attention span and fear of loud noises, this is rather impossible. Ben's mother constantly wonders what it would be like if Ben could do things like other children his age. The most stressful part of having a child with ASD for Bobby's mother is always thinking about everything she does and how it will affect Bobby. For Wayne's parents, the most stressful part of having a child with ASD is knowing their child is different and cannot communicate like other children his age. They get stressed out because they constantly worry if the ways they handle Wayne's ASD symptoms are benefiting or hurting him.

In the fourth part of the interview, questions seven through nine were about coping with stress. Question seven asked parents how they coped with any stress they may have experienced due to their child's ASD. Ben's mother said she and her husband tend to keep emotions and stress bottled up inside. Bobby's mother shared that she meets with a counselor and takes medication to help relax her. Wayne's parents said they do not do much to cope with the stress they experience. When asked about their feelings on ASD support groups in question eight, parents gave a variety of answers. Ben's mother stated she is interested in support groups, but is not part of one due to the lack of availability in her area. Bobby's mother believes support groups are a great way to alleviate stress by getting to know other parents that are in a similar situation that she is in. However, Wayne's mother blames a bad support group experience as her reason for not liking support groups. She also feels she would not regularly attend supports groups due to the lack of time she has. Question nine asked parents to describe the ideal way for them to cope with their stress. Ben's mother would like to be a part of a support group because she feels it would be settling to know that she is not the only one going through what she goes through on a daily basis. She feels speaking with a counselor would be beneficial as well. However, the counselor would have to have a background in ASD for her to really open up about her experiences with Ben. Bobby's mother feels as though she is already coping with the stress in an ideal way by being an active member in a support group and taking medication to relax her. In contrast, Wayne's mother feels she does not experience enough stress that would require her to find a way to cope with it.

Question ten asked parents to identify what ASD taught them as a parent as well as a member of our society. Ben's mother stated ASD has taught her patience and tolerance of others. She feels she has a better understanding of those who are different. Having a child with ASD taught Bobby's mother patience and acceptance of other children with special needs. Wayne's mother learned quickly to not be embarrassed of her child's actions and patience. She also learned that parents who have children with special needs devote a lot of time to their child's education. In question twelve, parents were asked to name one thing they wished everyone knew about ASD. Ben's mother wished people knew to ask questions about Ben instead of forming their own conclusions about him. Bobby's mother wished everyone knew that a child with ASD is first and foremost a child. Wayne's parents wished everyone knew ASD is a disability and not a disease.

Table 4

Parents Current Living Situation Questions and Responses from Parent Interview

Question	Parent Response
#1: How has ASD affected your family financially?	A: Waiver paid for most, they pay a little extra for groceries because of Ben's limited diet. B: Waiver paid for most, they paid for some of the treatments and materials for a therapy room. C: Waiver has paid for everything
#2: Do you and your spouse work? How often?	A: Dad works long hours & mom stays home. B: Dad works normal hours & mom took lower paying job to have flexible hours. C: Dad works 4 nights/week & mom works 4 days/week.
#3: How has your child's ASD affected your relationship with your spouse?	A: Mom feels as though they share the two older children, however she is in charge of Ben and dad is in charge of their youngest child, Jay. B: They have no time to spend with each other. C: They have disagreements on how to handle some of Wayne's behaviors.
#5: In what ways has ASD affected you?	A: Mentally- always trying to find ways to make Ben's symptoms milder. Physically- exhausting. Emotionally- having others criticize the way she handles Ben. B: Mentally- losing patience & feels more forgetful. Physically- not caring for herself, has gained 70 lbs. Emotionally: mom is more sensitive to the special needs community. C: Mentally- constantly being an advocate for Wayne. Emotionally- stressful having a child not able to communicate like other kids his age.
#6: In what ways did ASD make your life more stressful?	A: Feels like entire home is on pins and needles all the time. Constantly wishing he would be able to do things like other children his age. B: Always thinking about what she did and what effects it might have on Bobby. C: Knowing their child is different, wondering if they

	were handling Wayne's behaviors appropriately & not having a child that communicates.
#7: If you experienced any stress, how did you cope with it?	A: Bottle up emotions and stress. B: Met with a counselor and took medications. C: Did not do much to cope.
#8: What are your feelings on ASD support groups? Would you or have you ever joined a support group?	A: Interested in support groups, not part of one. B: Loves support groups. C: Did not have a good experience at a support group, but likes the idea of talking to other people who have experience with ASD.
#9: What would be the ideal way for you to cope with the stress you experienced because of your child's ASD?	A: Support groups, talking to counselors that are familiar with ASD. B: Support groups and medication. C: Doesn't feel she experiences much stress to need a method to cope.
#10: What has ASD taught you as a parent? As a member of our society?	A: Patience, tolerance of others. Understanding of those who are different. B: Patience. Acceptance of other children with special needs. C: Patience, not to be embarrassed. Parents of children with special needs are very involved with their child's school.
#12: What is one thing you wished everyone knew about ASD?	A: To not be afraid to ask questions, they would rather have someone ask them a question about Ben than come up with their own conclusion about him. B: A child with ASD is first and foremost a child. C: It is a disability and not a disease.

Your Child

This part of the parent interview focused on the child with ASD. The first question in Table 5 had parents identify what they felt their child's weaknesses were and most importantly, how it affected them. Ben's weaknesses include communication, comprehending and understanding concepts slowly and being able to understand other people's emotions. Ben's weaknesses really makes it clear to his mother that their family is not normal. She feels Ben may never have the life he deserves because he cannot communicate or respond appropriately in social situations. Bobby's weaknesses are being impulsive, constant talking during inappropriate moments and being short tempered. His weaknesses make his mother feel extremely frustrated. Wayne's weaknesses include communication skills, having a short attention span and his lack of socialization with others. His parents feel sad when they seem him struggle, but seeing him succeed at something makes up for it.

Question four asked parents to elaborate on their child's emotional makeup. Ben is usually calm until something sets him off. Once he is upset, it is hard to calm him down without completely removing him from the situation. Wayne tends to be a happy child until he is told "no." He can also become easily frustrated. Wayne rarely shows any emotions.

Parents were asked to name the different kinds of treatments their sons received in question six. Ben participated in Birth to 3, Wisconsin Early Autism Project, Reaching Your Potential and is currently receiving respite care. Bobby participated in an early childhood program, Floor Time Therapy, private tutoring, psychotherapy sessions and currently has personal care attendants that help him with his daily living skills. Wayne participated in Birth to 3, an early childhood program, Wisconsin Early Autism Project and is currently part of Reaching Your Potential.

Question seven of part five asks parents to identify the biggest improvement their child has made and also had them describe how it made them feel. Ben's greatest improvements thus far include his speech skills and being able to converse with another person. Ben's eating habits have also improved; he is more apt to try new foods now. He also stopped using self-stimulation to calm his body down. All of Ben's improvements give his parents a more positive outlook for the future. Bobby's writing skills have improved dramatically. His mother was thrilled when she saw a sentence Bobby had written completely on his own. Seeing him succeed, gives his mother hope that he can accomplish tasks independently. Wayne's parents are proud to see him make great strides in cognitive skills and being able to recite his personal information when asked. Seeing Wayne improve gives his parents hope for his future and reassurance that they could easily get through anything.

The last question of the interview has parents describe their dreams and aspirations for their child. Ben's parents hope that he will live as normal as a life as he can. They want him to have friends and experience all the things that friends do together. They wish for him to become independent so that he can graduate, get a job, get married and have a family someday. Bobby's mother would like him to experience what having a close friend really feels like. She also wants him to live in a home on his own and earn a job he loves. Wayne's parents hope he will grow out of his quirks soon and become independent and successful in whatever he chooses to do.

Table 5

Your Child Questions and Responses from Parent Interview

Question	Parent Response
#3: What do you feel your child's weaknesses are? How do they affect you?	A: Communication, learning slowly & understanding emotions. Makes mom feel as though their family is not normal. B: Being impulsive, constant talking & being short tempered. Can be extremely frustrating. C: Communication, short attention span & not being social. Sad to see him struggle.
#4 : What is your child's emotional makeup like?	A: Usually calm, less something sets him off B. Very happy unless he is told no and can be easily frustrated. C. Rarely shows any emotions.
#6: What kind of treatments/therapies has your child received?	A: Birth to 3, Wisconsin Early Autism Project, Reaching Your Potential & respite care. B: Early Childhood program, Floor Time Therapy, private tutoring, psychotherapy sessions & personal care attendants. C: Birth to 3, Early Childhood program, Wisconsin Early Autism Project & Reaching Your Potential.
#7: What is the biggest improvement	A: Speech, eating habits, self-stims has ended. Gives

your child has made since a diagnosis has been made? How has this made you feel?	them a positive outlook for the future. B: Writing skills. Gave mom hope that he can make improvements in what he does. C: Cognitive skills are improving & he knows his personal information. Gave them hope that they could get through it.
#8: What are your dreams and aspirations for your child?	A: Hopes Ben will live independently and as normal as he can and have friends. B: Hopes Bobby will have true friends and become independent. C: Hopes Wayne becomes independent and successful in whatever he does.

Conclusion

This chapter clearly illustrates how ASD affects the lives of parents. Each part of the parent interview added to the bigger picture of the impact ASD has on parents. In addition, clear representations of the parent's responses to pertinent interview questions were defined through brief summaries of how the parents responded as well as through the use of tables.

Chapter V: Discussion

Introduction

The purpose of this study is to determine what kind of impact the diagnosis of ASD can have on parents and what can be done to decrease the amount of stress these parents experience. This study focused on the impact ASD has on parents, specifically, emotions parents experience and factors that cause stress within a family directly impacted by ASD. The literature review within this paper stated many ASD related factors that cause stress as well as a variety of emotions that may be experienced from the stress of having a child with ASD. Parent interviews were conducted to find out more about three families in western Wisconsin. This chapter will identify similarities and differences between the families and the data collected from the research in the literature review.

Limitations

Limitations that may have affected the sample selection process could have included finding an ample amount of willing participants who met the specified criteria to participate in an interview in the western Wisconsin region. The participants must have met the following criteria: must have at least two children including one child with ASD; the children with ASD in the families should be around the same age and have a similar symptom level of ASD. Limitations that may affect the interview method included the varied way the parents chose to answer the questions and the amount of information they were willing to share for each question.

Similarities and Differences Found in the "Basic" Part of Interview

All of the families that participated in the interview were from western Wisconsin. The parents of the children with ASD were married and between the ages of 28 and 40. The children with ASD were all males and each had at least one sibling. Two of the males were the oldest of two children and one male was the third oldest of four children. The three males were all diagnosed between the ages of two and a half and three years of age. The literature review stated that ASD is more common in males and is usually diagnosed by the age of three.

Similarities and Differences Found in the "Diagnosis" Part of Interview

This section of the parent interview illustrated many similarities and differences between the families. Before being diagnosed with ASD, all of the parents described different situations that made them think their child was not developing typically. Parents began to notice their children were developing differently between the ages of a year and a year and a half. Each parent experienced visiting at least two or more professionals before having their child officially diagnosed. After hearing the diagnosis, the parents felt many different emotions. Though it gave some parents a sense of relief, hearing the official diagnosis was inevitably depressing. Two of the parents felt sadness when they thought about their child not being able to live a normal life. One couple felt sad thinking about how their child was the only one of 36 grandchildren to have special needs. A statement from the literature review can be easily related to how the parents that were interviewed felt. Experts on the treatment of autism (Koegel & LaZebnik, 2004, p. 5-6) said, "Over the years, I have talked with thousands of parents of children with autism, and I can tell you that getting the news is horrific, terrifying, stressful and, depressing."

The interviewed parents were asked to describe their experiences of going through the stages of grief. All of the parents did not go through all the stages of grief nor did the parents experience the stages of grief in the same order. As stated in the literature review, "People experience the stages of grief differently because there is no sequential order in which each stage should occur and because some people may not experience some of the stages" (Gibson, 2004). All parents experienced shock and anger. These two emotions can be closely related because parents were shocked to find out something was wrong with their child and then angry because they wondered why this would happen to their child. Two out of three of the mothers interviewed say they have accepted the diagnosis of ASD, whereas one mother has yet to go through the acceptance stage. The literature reviews states it may take many years before a parent can go through the stage of acceptance. After coming to terms with diagnosis, the two parents who accepted the diagnosis felt as though their child was just their child and they were not going to let a label take that away from them. The parent who has yet to accept the ASD diagnosis found herself researching ASD to find ways to help her son.

Similarities and Differences Found in the "Life After Diagnosis" Part of Interview

After hearing the diagnosis of their child, two out of three of the parents claimed to have made changes in their life. They acknowledged making changes to the way they interacted and communicated with their child with intentions of their child learning from their actions. One mother said they had changed their environment to make it less cluttered, safer and more child-friendly. There was one parent who said they did not many any significant changes within their household.

It was evident that the age of the siblings had a large impact on how they felt about their brother with ASD. The older siblings of one child had an idea of what ASD is and knew their brother was different. However, the three younger siblings were all too young to grasp the concept of ASD. Two of the siblings, ages two and four, were oblivious to the fact that their older brother had ASD since they do not know anything different.

After hearing their child had ASD, parents are thrown into a whirlwind of events right away and are supposed to make decisions that will help shape their child's future. The time and energy parents devote to find intervention programs for their child with ASD while caring for that child and/or their siblings places stress on the family (Ericzen, Brookman-Frazee & Stahmer, 2008). Two of the children were part of their local Birth to 3 program and one child went into an early childhood program. Since none of the parents had prior knowledge about ASD, all of the intervention programs were foreign to them. The parents expressed how confusing and frustrating the whole process was.

Similarities and Differences Found in the "Current Living Situation" Part of Interview

The responses to the questions within this part of the interview made it evident that ASD has a substantial impact on parents. As stated in the literature review, parents with children who have ASD may struggle getting through daily routines and may need to make personal sacrifices, while balancing a family life, spousal relationships and job obligations because their child has been affected by ASD.

All three families stated the Wisconsin Children's Long-Term Support Waiver has immensely helped with financing ASD treatments and therapies for their sons. Although, two of the families felt they were affected financially by ASD because they paid for things that benefit their children that the waiver did not cover. Financially speaking, one parent took a lower paying job that would allow her more flexibility to attend meetings and appointments concerning her son. As described in the literature review, financial stress can cause many problems for a family.

The parent interviews also revealed all of their marriages felt some kind of an impact due their child's ASD diagnosis. Sadly, the impact made on their relationship was far from being positive. Authors in the field of autism stated, "Parents of children with ASD report more symptoms of anxiety and marital dissatisfaction than parents of children with other types of disabilities" (Bedesem, Boyd & Mancil, 2009, p. 523). Though the parents interviewed experienced some marital dissatisfaction, all of the parents have remained in a stable relationship with their spouses.

When it came to coping strategies, parents revealed a variety of answers. One parent was very open to ASD support groups and has been a member of one for a few years. Two of the parents said do not anything to cope with their stress because they bottle up their emotions. However, a commonalty was found when asked about ideal coping strategies. All parents felt talking to others would be beneficial. Moreover, there was a consensus that the person they would talk to would have to be someone who had personal or professional experience with ASD. One mother said she would not be able to whole heartedly participate unless they had some common grounds. All but one mother felt that support groups would be the most ideal way to cope with their stress. The mother who was not in favor of support groups was open to talking to others about their experiences with ASD. However, as stated in the literature review, there may be some downfalls to support groups such as the availability and access to meetings in their area. "Coping strategies are related to the resources to which [parents] have access. Without these resources, parents are vulnerable and more likely to be stressed" (Hevey, Honan & Tehee, 2009, p. 34).

Parents were asked to identify what ASD has taught them, both as a parent and a member of our society. As parents, ASD has taught all of them a lesson or two about patience. As members of our society, the parents described different ways in which they have become more aware of the special needs community and all the time that parents of special needs invest into their child. There was a common theme when parents were asked to name one thing they wish everyone knew about ASD. All of the parents want people to be more accepting and open to

ASD. Though parents worded their responses differently, they all shared that same theme of wishing people could be more accepting.

Similarities and Differences Found in the "Your Child" Part of Interview

The last part of the interview dealt with questions specifically about the children with ASD. Parents were asked to identify how their child's weaknesses affected them. As expected, seeing their children struggle made the parents feel sad and frustrated. In contrast, when parents were asked to describe how they felt when their child made improvements, they all expressed the same feeling. The feeling they expressed was hope. Hearing about and seeing their children make improvements gave parents the sense of hope that their children could succeed.

The last question of the interview asked the parents to describe their dreams and aspirations for their child. All of the parents hoped their children would eventually learn how to live independently. Another similarity in their responses included hoping their children would experience what it feels like to have true friends.

Recommendations

Researching information about different coping strategies within the literature review as well as interviewing parents about their preferred coping strategy proved that all parents cope with their stress in different ways. In the end, it is the parent's ultimate decision on what they consider is a comfortable means of coping. From the parent interviews, it was apparent there was a need for some sort of coping strategies. There was a consensus that parents would like to talk to others who have experience in ASD – whether it is professionally or personally.

With this information established, parents of children with ASD need better access to support groups and professional help. The next logical step is to establish contacts to make these ideal coping strategies accessible to all families in need. From there, parents would be able to take advantage of speaking with others who have experience with ASD.

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APPENDIX A: Diagnostic Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
(b) failure to develop peer relationships appropriate to developmental level
(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
(d) lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
(c) stereotyped and repetitive use of language or idiosyncratic language
(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
(b) apparently inflexible adherence to specific, nonfunctional routines or rituals
(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(1) Social interaction
(2) Language as used in social communication
(3) Symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: *Diagnostic and Statistical Manual of Mental Disorders; Fourth Edition,* 2006

APPENDIX B: Letter to Members of the Chippewa Valley Autism Society.

Hello!

First of all, thank you for taking the time to read this letter! My name is Maggie Olson and I am a current graduate student at UW-Stout. I received my Bachelor of Science degree in Early Childhood Education in the spring of 2008. In the fall of 2008, I began working on my Master of Science degree in Education. While taking courses for my Master's degree, I also chose to work toward a certification in Early Childhood-Special Education.

Currently, I am a teacher at the UW-Stout Child and Family Study Center. I teach an amazing group of 3-4 year olds while overseeing college-aged students working on their ECE degree. I am also in my last semester of the Master's program.

To meet the requirements to graduate, I must write a thesis paper on a topic of my choice. I chose a topic that truly intrigues and interests me - autism spectrum disorder. Last fall, I wrote an article entitled, "Strategies for Working with Children with Autism" which was published in PACE magazine. At the end of April, I will be presenting about autism at Stout's annual Early Childhood Conference. There is a lot of research about children with autism, so I decided to focus on parents whom have children with autism. Thus, the topic and title of my thesis is "The Impact Autism Spectrum Disorder has on Parents."

I am seeking parents who have children with autism to help me with my thesis by participating in an interview about the ways autism has impacted their life thus far.(To make my study more consistent, their child with autism must have been diagnosed with ASD for at least three years and they must have at least one other child.) There are a total of 38 questions that must be answered. The method (in person, over the phone, or email) of how the interview is conducted would be determined by the interviewee to fit their schedule. From my study, I would like to learn how ASD impacts the lives of parents, determine similarities and differences amongst the parent's responses, and help find strategies that would decrease the amount of stress (if any) that these parents experience. If you are interested in participating in an interview or have any questions, please contact me by email: olsonmag@uwstout.edu or phone: 608.769.4406.

Again, thank you for taking the time to read my letter... and Happy Autism Awareness month!

Sincerely,

Maggie Olson

APPENDIX C: Interview Questions

ASD Questions for Parents

A) Basic Questions

1) How old are you and your spouse?
2) How old is your child and at what age were they diagnosed with ASD?
3) What are the ages of your other children?

B) Diagnosis Questions

1) When did you realize your child may not be developing typically?
2) Did you compare your child's development to that of your other children?
3) After you realized your child was not developing typically, what did you do?
4) What was your reaction to hearing your child's diagnosis?
5) Did you go through the stages of grief?
    Shock –
    Denial –
    Anger –
    Guilt –
    Depression –
    Acceptance –
6) Did you know anything about ASD prior to your child's diagnosis?
7) Do you feel anything positive came out of hearing your child's diagnosis?
    a) How did this make you feel?
8) What was the worst part of hearing your child's diagnosis?
9) What were your thoughts/emotions when you brought your child home for the first time after their diagnosis?

C) Life After Diagnosis

1) Did your parenting ways change after you learned your child had ASD? If so, how?
2) How did you tell your other children about their sibling with ASD?
    - What were their reactions?

- How do they currently feel about their sibling with ASD?

3) How did you tell other family members about your child with ASD?

    - What were their reactions?

        - On father's side –

        - On mother's side –

4) How soon after the diagnosis did your child begin receiving treatments?

5) What was the first kind of treatment your child received? How long did it last?

6) Were there any disagreements between what kind of treatments your child should receive?

D) Parents Current Living Situation

1) How has ASD affected your family financially?

2) Do you and your spouse work? How often?

    - Mother

    - Father

3) How has your child's ASD affected your relationship with your spouse?

4) What are the major differences – in general - now from when you first found your child had ASD?

5) In what ways has ASD affected you – mentally, physically, emotionally, etc.?

6) Looking back, in what ways did ASD make your life more stressful?

7) If you experienced any stress, how did you cope with it?

8) What are your feelings on ASD support groups? Would you or have you ever joined one?

9) What would be the ideal way for you to cope with the stress you experienced because of your child's ASD? (support groups, talking to counselor, etc.)

10) What has ASD taught you as a parent? As a member of our society?

11) How do you think our society views ASD? Why do you feel this way?

12) What is one thing you wish everyone knew about ASD?

E) Your Child

1) What is a typical day like for your child?

2) What do you feel your child's strengths are?

3) What do you feel your child's weaknesses are?

    a) How do your child's weaknesses affect you?

4) What is your child's emotional makeup like?

5) Describe your child's school situation – if attending school?

6) What ASD treatments/therapies has your child received? How did your child benefit from each?

7) What is the biggest improvement your child has made since a diagnosis was made?

    a) How has this made you feel?

8) What are your dreams and aspirations for your child?