“I WOULDN’T CHANGE ANYTHING”: THE EVERYDAY REALITIES OF LIVING WITH AUTISM FROM A PARENT’S PERSPECTIVE

by

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SIGNED: Rudy M. Molina, Jr.
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For my supportive family, loving wife, and beautiful children:

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To my mother for her unconditional love throughout my life and always believing in me no matter what struggles I faced as a different learner. Her commitment to me and the family will
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this journey, but I have since realized that my goal all along has to been to put myself in a position to spend as much time with my family as possible for the remainder of my life. I look forward to spending hours, days, and years doing the things we enjoy most.

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ABSTRACT

Using qualitative methods, this study is about the attitudes and daily practices of parents who genuinely want the best for their children who have been diagnosed with autism. The study examined the everyday realities of living with autism from a parent’s perspective. The purpose of this study was to describe the range of specific behaviors, practices, attitudes, and ways of being that families adopt when they engage in the world of autism. Three families were interviewed in these case studies. A content analysis of the interviews identified five thematic clusters that are described and examined in close detail. The five thematic clusters include (1) managing the diagnostic process, (2) child’s behavior and educational needs, (3) impact on parent’s well-being, (4) impact on the family as a whole, and (5) full integration into mainstream society. These themes were further categorized according to the “challenges” facing the families and the specific “strategies” families used to face these challenges. Parents shared their stories with the researcher with the hopes that their life experiences could be beneficial to other families facing the same challenges as they navigate complex educational, health, and social systems. The research presents a set of recommendations that were embedded in the participants’ stories. These recommendations represent advice from the parents in the study to other parents with children diagnosed with autism. Their recommendations are based on what the participants have learned as they raised their own child with autism.
I – INTRODUCTION

The impact of the autism diagnosis reverberates through the child, parents, family, community, and society. Often times, before a diagnosis is made, clinicians fail to recognize autistic characteristics or mistake them for other conditions when they are first observed, resulting in a delayed diagnosis (Lainhart, 1999). This can cause even greater levels of anxiety and frustration for the individual, family, and the parents. When a diagnosis is finally made, this usually triggers a complex set of emotions for parents. These emotions often include grief, sorrow, shock, denial, blame, and even questioning one’s purpose in life (Aylaz, Yilmaz, & Polat, 2012; Lutz, Patterson, & Klein, 2012). When parents go through this grieving process it is often due to the feeling that they lost a “typical child”. In an attempt to mask their emotions, parents often find themselves experiencing chronic sorrow, particularly as the child ages (Lutz, Patterson, & Klein, 2012). It is common for parents to encounter diagnoses between two or more clinicians to be unreliable (Daniels, Rosenberg, Law, Lord, Kaufmann, & Law, 2010; Mahoney, et al., 1998), which can cause greater levels of frustration forcing families to feel they are constantly battling against the health care and education systems.

Often, parents experience a disconnect between their own expectations (and those of society) and the lived realities of autism. The realities of autism can be startling and disruptive to the family’s overall sense of harmony. Parents find themselves having to learn aspects of health care, educational, medical, behavioral techniques and a range of other disciplines and industries in a very short time. This becomes difficult for them to manage because what they thought to be their priority – raising their children and supporting their family – is redefined on-the-fly to include the above plus learning about disciplines and techniques that others who would otherwise dedicate their whole professional careers to. Essentially, a mother or a father of a child with autism has to become a Jane or Jack-of-all-trades, in a very short amount of time. The
parents’ experiences with autism involve complex procedures of care and present constant and new challenges each day. It requires an enormous amount of psychic attention due to the duration and permanence of the situation. Parents eventually come to realize that there is not a cure for autism, that science is far behind, and that it will be a lifelong endeavor to care for their child. This new-found awareness can create a feeling of overwhelming despair and can even lead to lack of self-care on the part of the parent. In extreme cases, the levels of tension and frustration can get so high that couples find themselves at odds, and in many cases divorced (Neally, O'Hare, Powers, & Swick, 2012).

There seems to be a balancing act that every family must go through in order to cope and manage the day-to-day realities of autism. There are both stresses and benefits as a part of the reality. Parents and children are charged with the task, whether they realize it or not, of identifying the stresses and managing them while at the same time attempting to enjoy the fruits of their labor. Families who go through this process often feel that they have adapted well and in many cases feel that they have overcome their challenges. Parents learn and develop a range of strategies that allow them to handle very complex, fast-paced, and emotionally-charged situations. Parents find themselves restructuring the way they rear their children, their daily schedules, and the way they interact with family members, friends and society as a whole. It can be common for parents to experience emotional benefits to having a child with autism. Some families experience greater insight and perspective on their world view, values and priorities in life.

For many parents, the positive aspects of autism can outweigh its harsh realities. Just when the parents think they have just mastered it all, then comes adolescence and adulthood. During this next phase in life, parents encounter a new set of challenges that are related to
puberty, increased educational expectations, and the constant worry of, “what will happen when I am no longer around as a parent?” In spite of the complex challenges faced by parents, and in some cases because of these circumstances, they are able to successfully find ways to cope, manage, and in some cases overcome the challenges of autism. Conversely, there are also many other families who continue to struggle and find themselves and their families in greater despair than ever before.

I approached this study as a professional in the field of learning and attention challenges. Currently, I am the director of an academic support program that serves college students with a history of learning and attention challenges, most of whom are officially diagnosed with learning disabilities (LD), attention deficit/hyperactivity disorder (AD/HD), autism spectrum disorders (ASD) or other related conditions. As an administrator, it is my role to work with a range of constituents, including the parents of children with autism. In my effort to support students, I often find myself helping parents to manage their expectations, emotions, thoughts, and actions related to their child, spouse, family, the University, and life in general. These family cases inspired me to pursue greater understanding of the parents’ perspective.

I was diagnosed with an auditory processing disorder in elementary school, where I received a host of support services, including five years of speech therapy. It was my mother who was the first in my immediate family to recognize that something was different and it was she who helped me build strong self-advocacy skills to help me articulate my needs in and outside of school. As much as I attribute much of my own professional success to my mother, I found myself at a point in my professional career curious about what her own lived experience was as she raised me. For instance, how she navigated the complex web of educational, medical, and societal demands placed upon her. The more I reflected on my clients’ parents, the more I
wanted to learn about my mother’s experience; and so my research began. Additionally, as a father of two young boys, I am even more aware of the social and academic situations that children face each day. My role as a father can be very complex and full of challenges. For these reasons, and perhaps many more unidentifiable ones, my life experiences and present professional relationships have led me to this research.

**Purpose of the Study**

The purpose of this study is to identify the everyday realities of living with autism from a parent’s perspective and to describe the range of specific behaviors, practices, attitudes, and ways of being that families adopt when they engage in the world of autism. The study seeks to explore the experiences of parents whose children have been diagnosed with autism.

The parents who participated in this study were willing to share their stories because they believed it would be of value to other families and parents who are going through similar experiences. They are willing to disclose very personal, sometimes intimate, experiences they have gone through over the years.

I will draw from existing literature to generate greater understanding in the field with the intent to guide and inform practice for parents. This knowledge may also be helpful for practitioners and services providers within agencies to provide a perspective that may not be as readily available when first engaging with the parent client. Most of the literature focuses on the children, whereas this study purposefully focuses on the parents’ perspective. I was motivated by my work to understand the literature and to be able to inquire if the findings of other researchers would provide greater understanding for me and my program as we support parents and college-age students diagnosed with autism. This curiosity led me to dig much further, and led to in-depth conversations with people in my community. In turn, it afforded me the opportunity to gain greater understanding of the parents’ daily lives and the way they thought about their child,
family, and community as it relates to autism and life in general. During this process, I learned that the parents in my study had a great deal to manage as they raised their child from birth to adulthood. Lastly, this dissertation also includes recommendations for parents who are going through similar challenges, particularly for parents who have children who have been recently diagnosed with autism. These are drawn from the narratives produced by the participants in the study.

This research describes the attitudes and daily practices of parents who genuinely wanted the best for their child, regardless of the child’s perceived abilities or disabilities. It is a study that attempts to capture the parents’ story about how they were blessed with a child, the process of them realizing that their child was different, and the steps they took to ensure the optimal environment for their child’s success in and outside of the educational system. During this study, I found that each of the three parents either alluded to or directly stated that even though it had been a very difficult road to get to where they were by the time of our interview, they would not have changed it for any other scenario. They appreciated the journey they had taken, the richness their child has brought them, and valued how the various challenges made their family unit even stronger. Each of them admitted that it did not matter how successful they felt as a parent, there were still many days that they were challenged in new ways. However, each time they managed to find the resolve to push through in order to find solutions and opportunities for their child.

In the following chapters I will describe the research in further detail. Chapter two presents a review of the literature, which provides a brief historical outline of autism and describes studies that focus on the lived experiences of parents with children diagnosed with autism. Chapter three describes the methodological process used to identify the participants, collect, and analyze the data. Chapter four presents an analysis and description of the data. The
fifth and final chapter presents a summary of the findings and a set of recommendations by and for parents. These recommendations were derived directly from the participants themselves through their stories, insights, and direct quotes. All of the participants hoped that these recommendations would benefit other families with children diagnosed with autism.
II – REVIEW OF THE LITERATURE

This chapter is divided into two sections, the first outlines a brief history of autism and the second introduces the literature specifically on the impact of autism on parents.

History of Autism

Originally derived from the Greek word *autos*, referring to *self*, the notion of autism is described as *self*-ism. First termed in 1911, Eugen Bleuler (Kanner, 1973), a Swiss psychiatrist, thought of autistic characteristics to be a designation within the schizophrenia disorder. His observations of young children led him to believe that their withdrawal from the external world was the primary characteristic of autistic behavior.

Early Childhood Autism

More than three decades later, a research physician by the name of Leo Kanner at the Children Psychiatric Services within the Johns Hopkins Hospital, documented 11 case studies of child patients (Kanner, 1943), most of whom showing what was known at the time to be schizophrenic tendencies, or formally diagnosed co-morbid conditions. In his seminal publication, Kanner provided a rationale that Early Infantile Autism was an appropriate designation because it placed emphasis on the first manifestations of the disorder in the early years of life (Kanner, 1973).

Kanner provided three suggestions in order to further refine the autism designation. The first suggested that Bleuler’s description of “withdrawal” assumed that the patients had removed themselves from previous participation of social activity. Kanner (1973) wrote, "There is no withdrawal as in the accepted sense of the word, and a specific kind of contact with the external world is a cardinal feature of the illness" (p.95). As documented in the first 11 cases (1943), as well as more than one hundred other cases (Eisenberg & Kanner, 1956) it was suggested that one of the primary characteristics of autistic children is that they do not participate in social
interaction in the same way neurotypical children do. Although they may be aware of the act of delivering and receiving social cues, the autistic children do everything in their power to not respond to those cues. For if they did, it would mean that their desire to maintain sameness in their environment would be interrupted. This power of self-isolation was described to be so strong that even when a mother of an autistic child extended her arms to prompt the child to reach back, as a neurotypical child would, the autistic child was reactionless. In the event the child was picked up by the mother, and if the child did not carry out a tantrum, the child simply did not adjust his/her body to the form and shape of the mother’s hip or contour of her body, as if she was caring a plastic doll (Kanner, 1973).

The second observation made by Kanner (1973) was that the children were not shutting themselves off from the outside world; they simply exhibited low affect towards others. This was later described best when an autistic child was placed among other children in a room while playing independently with inanimate objects during the observed session. Later, when asked why he did not play with the other children in the room, the autistic child did not answer in a complete sentence, but instead began reciting facts about the other children. For instance, describing the color, texture, and other details of each of the children’s clothing; reciting all of the children’s names in the order in which he heard. It became evident to the researchers that the child had not shut himself off from the external environment. Instead, they learned that the child had paid a great deal of attention to the external world. The researchers concluded that keen observation was not for the mere activity of collecting facts, but for the sole purpose of sustaining sameness in his internal environment.

Lastly, Kanner (1973) went into great detail as to describe the relationship autistic children have with inanimate objects. It was thought by Kanner that this relationship was strong
because an inanimate object could not interrupt her environment when compared to her ability, or lack thereof, to control the actions of other adults and children. Similarly to the example above, if an object was moved or put out of place from its original position, the autistic child would either express frustration and/or do everything in her power to restore the original position of the objects. Kanner eventually concluded that autistic children were so concerned with the external world that they would watch with “keen photographic and phonic identity” to ensure a static environment at all times. Kanner’s observations and in-depth descriptions gave way to a new perspective on autism. His observations provided evidence that early infantile autism merited its own designation within behavior and psychological disorders, forever removing it from the schizophrenia disorder umbrella.

The shift from using “early infantile autism” to “early childhood autism” began around the early 1970’s when researchers began using the two terms synonymously to mean that early “childhood” or “infantile” autism was a clinically verifiable condition, showing its earliest symptoms before the age of three years (Daneel, 1974). One of the earliest publications that referenced early childhood autism was The Report of the Committee of Inquiry into the Treatment, Education and Care of Autistic Children in 1971. By 1974, the term was considered to be widely known and preferred (Tinbergen, 1974).

Asperger’s Syndrome

Hans Asperger, a Viennese pediatrician, began publishing his work just one year after Kanner’s first publication. It is believed that the two practiced, theorized and wrote independently from each other. Asperger wrote a paper on his clinical observations of several young boys that were referred to him for educational challenges in 1944 (Molloy & Vasil, 2012). In his original paper, Die “Autistischen Psychopathen” im Kindesalter (Asperger, 1944),
Asperger referenced the term Autistic Psychopathy. During a time in world history when Europe was being threatened by Nazi rule and the mass execution of those believed to be useless to society, including those with physical, psychological and cognitive disabilities, Asperger used his research platform to actively protest this perspective. He argued that those with such conditions were not only valued members of the society, but if given the best opportunity, they too, could be productive members. The primary aspect of his clinical designation was based on two criterion; first, the lack of interest in social interaction and the second being an abnormal use of eye gaze (Law Smith, Montagne, Perrett, Gill, & Gallagher, 2010).

Although Asperger worked and published around the same time as Kanner, Asperger had not reached international recognition the way Kanner had. Seventeen years after Kanner’s first publication, D. Arn Van Krevelen published the first case of Early Infantile Autism, making it the first of its kind to appear in a European journal (Van Krevelen, 1960). It was not until the 1960’s, due to Van Krevelen’s (1971) research, that Asperger’s work began to be recognized as part of the greater autism conversation.

In his 1971 article titled, Early Infantile Autism and Autistic Psychopathy, Van Krevelen compared and contrasted the two sets of descriptors used by both Kanner and Asperger and concluded that there is a clear distinction between the two conditions. Prior to this, many scholars had believed that Kanner’s descriptions of early infantile autism and Asperger’s description of autistic psychopathy were essentially the same condition. Among the seven pairs of compared descriptors, Van Krevelen called attention to two descriptors that were especially significant with regard to setting the two conditions apart. The first, being early infantile autism, was described as “psychotic processes, characterized by a course” (Van Krevelen & Kuipers, 1962) while Asperger’s autistic psychopathy was described by traits, which were believed to be
static (Van Krevelen, 1971). The table below provides a general description of the descriptors compared and contrasted.

**Table 2.1. Key Distinguishing Features Between Early Infantile Autism and Autistic Psychopathy.**

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Early Infantile Autism</th>
<th>Autistic Psychopathy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manifestation Age</td>
<td>First month of life.</td>
<td>Third year of life or later.</td>
</tr>
<tr>
<td>Motor and Speech</td>
<td>Child walks earlier than he speaks; speech is retarded or absent.</td>
<td>Child walks late, speaks earlier.</td>
</tr>
<tr>
<td>Language Use</td>
<td>Language does not attain the function of communication.</td>
<td>Language aims at communication but remains “one-way traffic.”</td>
</tr>
<tr>
<td>Eye Contact</td>
<td>Other people do not exist.</td>
<td>Other people are evaded.</td>
</tr>
<tr>
<td>World Perspective</td>
<td>The child lives in a world of his own.</td>
<td>The child lives in our world in his own way.</td>
</tr>
<tr>
<td>Social Prognosis</td>
<td>Social prognosis is poor.</td>
<td>Social prognosis is rather good.</td>
</tr>
<tr>
<td>Process vs. Trait</td>
<td>A psychotic process.</td>
<td>A personality trait.</td>
</tr>
</tbody>
</table>

(Van Krevelen, Early Infantile Autism and Autistic Psychopathy, 1971)

Between 1951 and 1962, Gerhard Bosch worked as a junior and senior psychiatrist at Frankfurt University in Germany. During this point in his professional career, he found himself to be increasingly interested in researching the autistic phenomenon among children (Bölte & Bosch, 2004). After working with patients for several years, he coined the term “Asperger’s Syndrome” in his first book published in 1962 (Bölte & Bosch, 2004). However, the book was originally published in German, making it less accessible to English readers. The monograph became so popular among the German medical community that it began to harness international interest. An English edition titled, *Infantile Autism - a clinical and phenomenological- anthropological investigation taking language as the guide* was eventually published eight years
later (Wing, 1986) and is now referenced as the first documented use of the term Asperger’s syndrome (Ishikawa & Ichihashi, 2007). The 1970 book featured five autistic cases, which provided Europe, and eventually the world, with its first set of European case studies that differentiated between early infantile autism and what we now refer to as Asperger’s syndrome.

Described by Lorna Wing in 1981, the switch from Autistic Psychopathy to Asperger’s syndrome was purposeful and forever impactful for both practitioners and patients. In her own words,

“The name he [Hans Asperger] chose for this pattern was autistic psychopathy, using the latter word in the technical sense of an abnormality of the personality. This has led to misunderstanding because of the popular tendency to equate psychopathy with sociopathic behavior. For this reason, the neutral term Asperger’s syndrome is to be preferred and will be used here.” (Wing, 1981, p. 115)

Wing, an English psychiatrist, who still practices medicine on a consulting basis, is credited for popularizing the term Asperger’s syndrome in her 1981 publication titled, *Asperger’s Syndrome: A Clinical Account* (1981). This article not only provided a rationale for renaming the condition but she also contributed to the literature by suggesting two modifications to Asperger’s account. She also synthesized the literature with regard to course, prognosis, etiology, pathology and epidemiology.

**Table 2.2. Significant Milestones in Autism Research**

<table>
<thead>
<tr>
<th>Year</th>
<th>Term</th>
<th>Key Researchers</th>
<th>Description of significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to 1911</td>
<td>Schizophrenia</td>
<td>N/A</td>
<td>Autistic symptoms were not distinguished in the literature from schizophrenia</td>
</tr>
<tr>
<td>Year</td>
<td>Description</td>
<td>Author</td>
<td>Note</td>
</tr>
<tr>
<td>------</td>
<td>------------------------------</td>
<td>-------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>1911</td>
<td>Autistic</td>
<td>Eugen Bleuler</td>
<td>First reference of autism in the literature; Withdrawal from social activity was the key marker</td>
</tr>
<tr>
<td>1943</td>
<td>Early Infantile Autism</td>
<td>Leo Kanner</td>
<td>Three key characteristics: (1) delayed language-development (2) social awkwardness (3) dedication to inanimate objects</td>
</tr>
<tr>
<td>1944</td>
<td>Autistic Psychopathy</td>
<td>Hans Asperger</td>
<td>Similar to Kanner’s, but noted less evidence of language delay</td>
</tr>
<tr>
<td>1970</td>
<td>Asperger’s Syndrome</td>
<td>Gerhard Bosch</td>
<td>Credited for first use of Asperger’s syndrome</td>
</tr>
<tr>
<td>1981</td>
<td>Autism Spectrum Disorder</td>
<td>Lorna Wing</td>
<td>Popularized Asperger’s syndrome term and placed the diagnosis on a spectrum of related disorders</td>
</tr>
<tr>
<td>1981</td>
<td>High-functioning Autism</td>
<td>Marian DeMyer</td>
<td>Preferred the term high-functioning autism because a group of pre-school children did not meet Kanner’s criteria</td>
</tr>
<tr>
<td>1991</td>
<td>Asperger’s research translated</td>
<td>Uta Frith</td>
<td>The first to translate Asperger’s original research German into English</td>
</tr>
</tbody>
</table>

Perhaps the most significant contribution she made in this publication was how Wing attempted to differentiate and relate early childhood autism, Asperger’s syndrome and schizophrenia to each other, allowing the ability to suggest that Asperger’s syndrome ought to be considered within the ‘spectrum’ of autistic disorders. Although some scientists (Wolff & Barlow, 1979; Wolff & Chick, 1980) were advocating to keep Asperger’s syndrome under the schizophrenia classification, Wing suggested that there was not much diagnostic and intervention utility. Instead, Wing (1981) suggested that “The aim should be not to enlarge, but to separate sub-groups from broad category and thus to increase diagnostic precision” (p.123). Wing’s goal was to assist the diagnostic community to have strong correlations between classifications so that
when a patient would go for a ‘second opinion’, the doctor would refer to the same criteria that
the first doctor used in her diagnosis.

The benefits of such positive correlations between the first and second diagnosis were
more significant than merely demonstrating agreement among the professional community.
Symbolically, the commitment to disaggregate and specify autistic behaviors would eventually
prove to be helpful for patients and their families. It turns out that Wing and her associates’ push
for refined classifications led to future studies that suggested there were, indeed, differences
between Asperger’s syndrome and early childhood autism. More specifically, in the 1990’s,
researchers began to find evidence that a whole new sub-classification of autism was emerging,
eventually termed high-functioning autism.

*High-functioning Autism*

As evidenced by the name change of the *Journal of Autism and Childhood Schizophrenia*
to *Journal of Autism and Developmental Disorders*, many changes in the field of autism were
taking place between the 1960’s and 1980’s. Although Elisabeth Newson had long been using
the term ‘more able autistic people’ it was DeMyer and associates who are credited to first use
the term high-functioning autism (Gillberg C., 1998). In a comprehensive review of the
literature, DeMyer and colleagues (1981) found that many researchers and clinicians were going
through a sort of metamorphic process with regard to how they used terms. For instance, in an
earlier study, DeMyer et. al. (1971a) used the term “early schizophrenia” to describe a group of
higher functioning preschoolers because, in their opinion, the children did not meet Kanner’s
criteria. Meanwhile, other researchers were describing similar observations and using the term
“infantile autism” for the same type of observations. In an effort to distinguish these supposedly
“higher-functioning” children from the others, DeMyer and colleagues (1981) introduced “high-
functioning infantile autism”, placing emphasis on the onset of these characteristics prior to the age of 30 months.

Although well-intentioned, the introduction of the term high-functioning autism has yet to offer significant meaning to researchers and practitioners. The jury is still out as to what role terms such as Asperger’s syndrome and high-functioning autism have on prognosis and intervention. As important as labels are to governmental and educational systems, they are much less important to practitioners focusing on the symptoms of the above disorders. As a result, more researchers are placing emphasis on a multi-dimensional, versus a categorical, view of autism-spectrum disorders (Howlin, 2004). In other words, “It is time to move away from potentially circular attempts to differentiate Asperger’s syndrome [and high-functioning autism] and [early childhood] autism. For the time being, in practice, the most useful indication of current needs and future prognosis is overall level of ability” (Leekham et al., 2000, pp. 26-27).

In short, there were several key figures throughout the history of autism research who attempted to better understand the phenomenon of autism. The historical line of events outlined above provide a brief look into the past of how our understanding of autism has evolved. In the next section, I will continue with this historical perspective by describing how autism has evolved as a classification and diagnosis in the medical community.

**Autism Defined**

Autism Spectrum Disorders are defined by the American Psychiatric Association (APA) (2013) and the World Health Organization (WHO) (1994) as neurodevelopmental conditions characterized by cognitive and behavioral difficulties in communication and social interaction and considered to be a low-incidence form of disability. The *Diagnostic and Statistical Manual*
(DSM) has gone through an evolution and when its history is evaluated, it provides insight into the current state of mental disorders that is currently debated in the U.S. and abroad.

Table 2.3 Evolution of the DSM

<table>
<thead>
<tr>
<th>Year</th>
<th>DSM Version</th>
<th># of pages</th>
<th># of diagnostic categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1952</td>
<td>DSM</td>
<td>132</td>
<td>106</td>
</tr>
<tr>
<td>1968</td>
<td>DSM II</td>
<td>119</td>
<td>182</td>
</tr>
<tr>
<td>1980</td>
<td>DSM III</td>
<td>494</td>
<td>265</td>
</tr>
<tr>
<td>1987</td>
<td>DSM III - R</td>
<td>567</td>
<td>292</td>
</tr>
<tr>
<td>1994</td>
<td>DSM IV</td>
<td>886</td>
<td>297</td>
</tr>
<tr>
<td>2000</td>
<td>DSM IV – TR</td>
<td>943</td>
<td>365</td>
</tr>
<tr>
<td>2013</td>
<td>DSM V</td>
<td>947</td>
<td>TBD</td>
</tr>
</tbody>
</table>

The DSM provides medical and psychiatric professionals the description and criteria to diagnose a patient. The purpose of this manual is to standardize and create greater reliability between a patient’s first diagnosis and ‘second opinion’ diagnosis (American Psychiatric Association, 2013). The first edition was published in 1952 and it consisted of 132 pages, covering 106 disorders while the most recent edition is more than 900 pages and lists more than 300 disorders. Between 1952 and 2000, there have been seven editions with the most recent published in May 2013 (Flaskkerud, 2010).

In the fifth edition of the DSM, there are two diagnostic categories related to autism. The first is the Social (Pragmatic) Communication Disorder and the second is Autism Spectrum Disorder (American Psychiatric Association, 2013). In order for a diagnostician to conclude an individual has a Social Communication Disorder, four criteria that must be met. For instance, (1)
the patient must exhibit persistent difficulties in the social use of verbal and non-verbal communication, (2) functional limitations in social participation, (3) symptoms appear early in the child’s developmental period and (4) these symptoms should not be as a result of another medical condition (American Psychiatric Association, 2013).

Table 2.4 DSM-V Social Communication Disorder

<table>
<thead>
<tr>
<th>Use of Verbal and Nonverbal Communication</th>
<th>Social, Academic and Occupational</th>
<th>Early Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persistent difficulties in the social use of verbal and nonverbal communication</td>
<td>The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance – individually or in combination.</td>
<td>The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).</td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2013)

The newest edition of the DSM now has a single condition called Autism Spectrum Disorder (ASD), which merged the DSM-IV related disorders (autistic disorder, Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder – not otherwise specified) into one. For this diagnosis to be considered, a dyad of characteristics must be observable: (1) deficits in social communication and social interaction and (2) restricted repetitive behaviors (RRB’s), interests and activities. Since both criterion are required for ASD
diagnosis, then a social communication disorder would have to be considered if RRB’s are undetected (American Psychiatric Association, 2013).

Table 2.5 DSM-V Autism Spectrum Disorder

<table>
<thead>
<tr>
<th>Social Communication and Interactions</th>
<th>Restricted and Repetitive Patterns</th>
<th>Early Onset</th>
<th>Social and Occupational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persistent deficits in social communication and social interaction across multiple contexts</td>
<td>The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.</td>
<td>The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).</td>
<td>Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.</td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2013)

The United States federal law Individuals with Disabilities Education Act (IDEA) governs how states and public agencies provide early intervention services for children with disabilities (US Department of Education, 2004). IDEA reauthorization 2004 outlines the various educational needs of children with disabilities from ages three to 21, using 14 categories of disability. Among the related services Child Find mandates that each state in the Union must designate a lead agency, such as the Department of Education, to educate the public about early
intervention services and how to refer parents to these services. Public school districts are charged with the responsibility to provide educational support services for all students with disabilities who are deemed eligible for special education services and who reside within their home district, whether or not they are attending public schools. Parents have the right to be informed in writing of the Procedural Safeguards (US Department of Education, 2004). There are two tools that explain in detail what the legal and educational rights of parent with children with disabilities. The first is Whose Idea Is It Anyway: A Parent’s Guide to the Individual with Disabilities Education Improvement Act of 2004 (US Department of Education, 2010) and A User’s Guide to the 2004 IDEA Reauthorization (Consortium for Citizens with Disabilities, 2005). Together, these tools support the overarching goal, which is to create a process that encourages the parent and school of the child to work as a team in identifying and implementing the most appropriate Individual Education Plan (IEP) for the child.

One of the most highly debated issues with regard to autism has been the ability, or lack thereof, to distinguish between high-functioning autism and Asperger’s disorders. Howlin (2004) points out that there are two distinctions between the two: first, those who have been diagnosed with Asperger’s disorder have relatively normal cognitive skills and second, they do not have a delay in language. Howlin (2004) and others (Leekham, Libby, Wing, Gould, & Gillberg, 2000; Ozonoff, Rogers, & Pennington, 1991; Tryon, Mayes, Rhodes, & Waldo, 2006) point out that if criteria for autism are met, then autism takes precedence. According to several research studies (Eisenmajer, et al., 1996; Howlin P., 2003; Manjiviona & Prior, 1995; Mayes & Calhoun, 1999) “…most, if not all, who are diagnosed with Asperger’s disorder actually meet DSM-IV criteria for autism and not Asperger’s disorder, including all of Asperger’s original cases” (Tryon, Mayes, Rhodes, & Waldo, 2006, p. 2). Due to combining of the previous four diagnosis into one
in the new DSM, diagnosticians must use a social communication disorder or an autism spectrum disorder when considering an autism-related diagnoses.

Although the World Health Organization’s (WHO) *International Classification of Diseases* (ICD) was first published in the 1950’s, its history of development dates back all the way to the mid eighteenth century (World Health Organization, 2012). Today, the ICD-10 is used to diagnose mental disorders as well as causes of sickness and death and is the preferred diagnostic manual for researchers and practitioners outside of the U.S., but this is changing as the DSM is gaining ground on global distribution and continues to redefine how autism is characterized. Unlike the DSM, the ICD has not recently modified their criteria for diagnosing autism. Virtually the same criteria is listed in the current ICD as the DSM-IV when specifically referring to Asperger’s syndrome (Ozonoff, Rogers, & Pennington, 1991). To conclude with a diagnosis of Asperger’s syndrome when using the ICD, two out of the four criteria must be met in the social impairment category and one out of the four criteria must be met in the repetitive activities category.

Overall, there is a strong agreement that autism, high-functioning autism, Asperger’s disorder and other pervasive developmental disabilities are not distinct disorders, but instead reside on a continuum of autistic characteristics. However, there is still enough confusion among researchers that has not allowed for clear differentiation in symptoms, behaviors and diagnosis. As a result of this confusion, there have been instances when practitioners and diagnosticians have had difficulty in interpreting tools such as the DSM and ICD, making it even more challenging for the patient and their family (DeMyer, Hingtgen, & Jackson, 1981).

Although first conceived as well-intended, there is not any doubt that DSM and ICD have shaped how we view human ability and disability in our society. Critics of these manuals point
out a number of limitations. Many of these limitations are based on the fact that the manuals are derived from a medical and psychological model that is based on a deficit definition of human ability or inability. Similarly, Jacquelyn Flaskkerud (2010) suggested that mental disorders are not necessarily determined by the individual’s medical condition, but instead determined by the state in which society’s sociopolitical pendulum is swinging.

Flaskkerud explains, homosexuality was first considered to be a mental disorder, and so classified in the DSM II. By the seventh printing of the DSM II in 1974, the homosexuality disorder was replaced with “sexual orientation disorder.” Just six years later in the DSM III, the disorder was changed again. This time civil rights activists had put enough pressure on the APA to have the disorder read, “ego-dystonic homosexuality,” placing emphasis not on one being homosexual but rather having a distinguishable anxiety and preoccupation over one’s sexuality (Flaskkerud, 2010). The reference to homosexuality continues to be a controversial topic with regard to mental disorders and its classification in the DSM. Still to this day, the diagnoses related to sexuality and gender continue to evolve.

Alarcón and associates (2009) suggested that although the DSM IV-TR was an improved manual from predecessors, it fell short for several reasons. First, it failed to integrate reliable and comprehensive research on diverse populations regarding the listed mental disorders. Second, when adjusting for cross-cultural environments, it relied on decontextualized data that did not account for inter-cultural variance. Last, by using a simplified and linear framing of mental disorders, it contributed to a clinical phenomenon that resulted in “…essentialism, reductionism, and ethnocentrism” (Alarcon, Becker, Lewis-Fernandez, & et.al., 2009, p. 559). Wing and associates suggested that the DSM V is flawed because it has yet to include issues related to social imagination, recognizing infancy and adulthood diagnoses as well as the oversight that
girls and women with autism continue to be disproportionately unrecognized or misdiagnosed (Wing, Gould, & Gillberg, 2011).

Whether the practitioners are aware of these biases or not, there is greater chance for misdiagnosis. Researchers (Flaherty & Meagher, 1980; Muroff, G, Joe, & Ford, 2008; Segal, R, & Watson, 1996) have concluded that there are serious consequences to inappropriate diagnoses as a result of a lack of cultural sensitivity, such as greater rates of unjustified hospitalizations, increased prescription of antipsychotic drugs and greater use of restraints when unnecessary.

To balance the misrepresentations of autism characteristics and the potential inappropriate use of medical and psychiatric services, Alarcón and colleagues (2009) call for total infusion of a sociocultural perspective throughout the DSM. They suggest that there are benefits in doing so, as it will have a greater impact on each diagnostic encounter, not only for ethnic minorities, but also for women and the population who come from regional and cultural pockets of the country that differ from mainstream society. They also suggest that by moving the current “disclaimer” statement that currently is found in the appendix to the diagnostic criteria of the manual; it would encourage each practitioner to take a closer look at the patient’s cultural capital when determining the diagnosis. Last, they imply that without doing so, there is simply too much risk of misdiagnosing because the world-wide distribution of the DSM puts this diagnostic tool into the hands of practitioners from all over the world who are working with populations that are not likely to be represented in the research samples. Although it may be economically beneficial for the DSM and the ICD to be distributed globally, there is an opportunity and responsibility for the American Psychiatric Association and the World Health Organization to provide a comprehensive perspective on mental disorders as it relates to cultural practices and societal behaviors.
Parents of Children Diagnosed with Autism

There were several themes that emerged in the literature, some of which included the diagnosis process, the “invisibility” of autism and the isolation that was felt as a result; frustration and anxiety felt due to the responsibility and newly acquired roles and the learning process for parents.

Lynne Ray (2002) first used the phrase, “making the invisible, visible” when she studied parents with chronically ill children. Her findings showed that parents were constantly seeking a balance in life as a result of high demands from their children and the many other commitments that revolved around the family unit. The families ultimately used a series of strategies to find this balance; some of these included taking breaks in order to keep energy levels up and taking time as a couple to “refill the reserves.” Overall, Ray reported that although parents’ time was consumed by activities such as homework, grooming, medical and school visits, they found the resources and gumption to “just do it”. With high levels of vigilance, and commitment to a greater goal, parents expressed that they were prepared for the unknowns of autism.

Lindsey Hoogsteen and Roberta Lynne Woodgate (2013a) and David Gray (1993, 2002) also found evidence that parents had documented the invisible, visible phenomenon of autism. Hoogsteen and Woodgate (2013a) focused their research around rural parents with children diagnosed with autism. They found that the rural experience was similar to what urban studies (Cashin, 2004; DeGrace, 2004; Glass, 2001; Gray D. E., 1993; Gray D. E., 1994; Gray D. E., 2002; Woodgate, Ateah, & Secco, 2008) had previously documented but there were also a number of differences noted. For instance, when comparing their findings, it was particularly challenging for parents to learn about autism in rural communities because popular media, such as the televised news, simply did not provide information to the general public about autism or such conditions. Additionally, it was more difficult for parents to recognize characteristics about
their child that might have been different because they felt their communities were extremely small. Moreover, when they learned that their child had autistic characteristics, the diagnosis process was perceived to be inaccessible due to the physical distance between the families’ places of residence and the nearest clinic or facility where further testing could be done. Last, when the diagnosis was provided, parents reported that the health and educational systems were cumbersome and often very inefficient when accessing services. Parents from this study also reported that they wished that the practitioners and specialists could have been more supportive earlier on in the process because that is when they had the most questions (Hoogsteen & Woodgate, 2013b). Additionally, a simple follow-up phone call or an introductory book would have been greatly appreciated to help them better understand what it meant to have a child with autism. Instead, parents felt they were left alone in the big world of autism.

In his 1993 article, Gray (1993) identified three key themes that run through most of the literature, which include what he referred to as (1) negotiating the cure, (2) affection towards family and others and (3) the paradoxical relationship between uniqueness and institutionalization. Gray’s (1993) participants felt the immense anxiety and confusion related to not being aware and uneducated on what autism looks like, feels like, and the resources that can be associated with it. Gray provides the following quote as it illustrated the thoughts and emotions felt by a father who reflected on his child’s recent diagnosis:

That was the first time that someone had told me that there was something wrong with my daughter, and this is what it was. I’m not a big drinker by any means and I was so relieved…[that] at last I knew what was wrong with her that I went home and had half a bottle of rum—cried on my wife’s shoulder…At last I knew what
was wrong. At last they are going to do something, they’re going to help us.

In the study referenced above, Gray was comparing perceptions between parents and staff, and one of his findings was that parents often perceived affection from their child to be greater than when observed by the professional personnel. Gray’s stance is that although it is important for staff to have a broader perspective of children’s affection and other behaviors, it is just as important to recognize that the specific parent’s perspective toward their own child is the most important aspect for that particular family. In other words, regardless of whether the child is perceived less affectionate by the staff, it is more important for the parent to feel that the child is affectionate to them. By having this perspective as a clinician, it allowed the family to grow and develop according to their needs at the time.

Finally, Gray points out that parents of children with autism are often disappointed due to the lack of individualized support the parents feel is warranted based on their child’s needs. Parents tended to feel that their child’s case is unique enough to warrant a personalized approach, and that they should not have to request special attention in order to meet the basic needs of the child. Participants in Gray’s study suggest that the system should be able to recognize these unique characteristics and recommend appropriate services. Instead, parents felt ignored and one of many families on a long list of patients. To address this concern, clinicians and agencies are encouraged to take the time to identify the needs of each patient and openly discussing the characteristics of the symptoms that make that patient unique. Gray and others (Hoogsteen & Woodgate, 2013a; Gray D. E., 2002; Woodgate, Ateah, & Secco, 2008) refer to this as making the invisible, visible.
In conjunction with the notion of invisibility, parents often assigned the feeling of isolation to their child’s autism experience. Similar to the findings documented with Sandra Macky and Linda Goddard (2006), Woodgate, et al (2008) reported that parents felt as if they were living in a world of their own, having to find resources in their community and on the Web by themselves. Often times this translated to identifying the steps to access specific services, and then coming full circle to learn that they will have to do it all over again the following day and as new situations presented themselves. Parents felt particularly isolated when comparing their overall parenting experience with other parents who did not have a child with autism. They found that their unique challenges and frustrations were often times simply incomprehensible to other parents, resulting in a feeling of isolation. These researchers also found that over time and with experience, these same parents were successful in employing effective strategies to overcome their feelings of isolation, and in turn, used their strategies to promote healthy relationships with their families and others in the community.

The diagnosis process, which included the phase prior to official diagnosis, the evaluation itself, and the post diagnosis outcome, is another critical point in the long journey for parents of children with autism. Kenny Midence and Meena O’Neill (1999) pointed out that their participants began noticing characteristics that were different compared to other children in their family and in the community. Similar to what Sen and Yurtsever (2007) observed, Midence and O’Neill found that for some parents, there was unawareness of their autistic characteristics as a result of their parents not speaking openly about autism with their child. Moreover, it was also found that it was common for parents to be in a state of denial that their child could have a disability, and more daunting, it might be autism. Although many experienced guilt and despair, other parents found acceptance among their friends and community members, which helped
them achieve acceptance that their child was different and helped the family learn more about how to access services. The next phase Midence and O’Neill documented was when parents felt empowered by their new level of acceptance, they felt it was their obligation to get educated on the topic. This eventually led to greater benefits and peace of mind for themselves but more importantly they found ways to help their child be successful in school and in life. As parents learned more about autism, they gained greater levels of confidence, which led to better decisions and recognizing more opportunities for their child and family. This eventually led to a feeling of control rather than the anxious feeling that autism had taken control of them. Perhaps most significantly, this study demonstrated that as parents gained a greater understanding about autism, they also felt that they had gained a greater understanding of their child.

Several articles referenced the volume of work required to manage and support a family with a child diagnosed with autism (Hoogsteen & Woodgate, 2013a; DeGrace, 2004; Vickers & Parris, 2005; Cashin, 2004), and of these, a few studies discussed how the occupational role of parents, particularly mothers, was extremely overwhelming. Mothers felt that they had made a certain level of sacrifice in various areas of their life in exchange for tending to their child’s needs. These areas related to their professional careers, spousal relationships, and the needs of other children in the family (Scorgie & Sobsey, 2000; DeGrace, 2004). Scorgie and Sobsey (2000) demonstrated how mothers acquired new roles and responsibilities as a result of raising their child with autism. Similar to what Vickers and Parris (2005) and Cashin (2004) found, Scorgie and Sobsey (2000) were able to see that in order for parents to find balance and be effective in rearing their children, they often felt like they needed to put their needs aside and often times lived moment to moment. DeGrace (2004) also documented how this moment to moment feeling was overwhelming and caused high levels of anxiety. To combat this, both
DeGrace’s (2004) and Scorgie’s and Sobsey’s (2000) studies learned that parents relied on behavioral routines to control for at least some of the unknown aspects of autism. Some examples of the routines included brushing teeth at specific hours each day, waking up at the same time each day, and creating a checklist prior to leaving the house. When instituting such behaviors, parents began to observe small gains in their child’s development and their own confidence increased believing that they can survive autism. By making such adjustments and following these routines, parents reported they experienced that their child had enriched their life and they gained a newfound appreciation of what other parents had already gone through in order to have healthy children, families, and relationships with their partners. As they experienced greater success overall, these parents shared strategies with others, and when they did, they found that by educating and supporting others, they too, were rewarded by having more positive social interactions within their community. One of their most significant findings was that parents took great pride in the fact that they celebrated even the smallest gains, as these represented incremental progress toward a greater goal.
III – METHODOLOGY

This chapter outlines the methodological steps taken to conduct the study. To begin, I introduce the paradigmatic orientation. Next, I provide a description of participants, their living contexts, the data collection strategies used, how I addressed reciprocity, strategies for data analysis, the presentation of the data and the limitations of the study. Lastly, I describe the interpretive process I enlisted when making sense of the data.

Paradigmatic Orientation

Rooted in an interpretivist paradigm, I used qualitative methods to understand this particular phenomenon. The techniques used in this study revolve primarily around in-depth interviews, and the collection of select artifacts (Denzin & Lincoln, 2003; Marshall & Rossman, 1999). An analysis of the literature revealed an intersection between autism and how parents with children diagnosed with autism negotiated the demands and challenges of their associated life experiences. My goal was to showcase the perspectives of parents while placing emphasis on their spoken word, offering a venue for them, and myself, to make meaning of their real life experiences (Strauss & Corbin, 1990). The following research questions were identified:

1. What are the lived experiences of parents with children who have been diagnosed with autism?
2. More specifically, how do parents interpret their experiences in social, academic and educational settings related to their child’s autism diagnosis?

To answer these questions I drew upon three individual case studies. I used the case studies both as an analytic tool as well as a stylistic component of the thesis. The multiple case analysis used in the study served as a centralized point for meaningful understandings amongst all three of the cases.
I used a qualitative approach to explore the many possible interpretations of a naturally occurring phenomenon (Bogdan & Biklen, 2003). My research is an interpretive and naturalistic approach to bring meaning to a specific phenomenon in the world (Marshall & Rossman, 1999). The process required that I studied phenomenon that occur in their natural settings. By doing so, it allowed the actors within the phenomenon to reflect and come to realizations, understandings, and perhaps conclusions based on the experiences people brought to them. Next, I incorporated my own interpretations based on the data collected. This process can be best described as an inductive and cyclical process that reoccurs both simultaneously and concurrently, allowing for progress, insight and pause both on the part of the participant and the researcher. Ultimately, the process lead to a greater understanding for both parties, including an opportunity for the reader to generate her/his own interpretations.

Each human comes to understand her/his world through a subjective lens sometimes referred as a vantage point (Arias, 2008). Each vantage point provides a unique perspective of the world around us, often times providing the opportunity to expand our understandings and conceptions of the phenomenon. The range of unique perspectives is vital to making greater understanding to complex and interconnected happenings in our daily lives. From these unique perspectives come a diverse range of experiences and when asked, they manifest into different stories about the phenomenon. This process was also true as I embarked on my inquiry related to disability, family perspectives about ASD and the many associated educational experiences (Woodgate, Ateah, & Secco, 2008).

The Participants

The study was conducted in the southwestern part of the United States. I conducted a series of in-depth interviews with parents of children diagnosed with autism. My goal was to find three to five participant families. When identifying participants, my criteria required that parents
needed to have children with an official diagnosis of autism. The study required a relatively small commitment of time but it was important for me to explain that the time they spent with me would likely elicit a wide range of emotions as a result of the interview questions and perhaps the process of reflection. It was also made clear that in order to participate, they would have to be willing to verbally express their experiences, reflect on the meaning of outcomes and share other data sources (i.e., articles, photos, evaluations, etc.) when appropriate.

The recruitment strategy was one of convenience. I used my professional and social network as an educator in the field of higher education. When the opportunity presented itself, I openly shared my interest in the topic of autism. It was in these informal, social conversations that I learned about people’s experiences with autism. For instance, during a holiday party, I introduced myself and my family to a couple at the dining table. It turned out that once I told them I was a director of a program that provided academic support to college students who learn differently and that my doctoral work is on autism, they both looked at each other and said, “We have a seven year-old son who was recently diagnosed with autism…” My connections to the University campus provided an additional level of credibility and convenience. After initiating the interview process with one participant, he referred another family to me, eventually meeting my goal of potential participants for my study. This snow-ball effect (Marshall & Rossman, 1999) proved to be an effective approach, as it allowed my credibility to build from my first family to several along the way. By tapping into existing, albeit new, relationships, families felt comfortable and safe to share their story with me.

My study focused on middle to upper class parents who had several years of experience in the world of autism as a result of their child’s diagnosis. Two families were European Americans and the third family was Asian American. All of the parents were associated with the
University in either faculty or administrative roles, or both. The parents’ ages ranged from early 40’s to late 60’s and the children’s ages ranged from 7 years to 30 years of age, all of whom were diagnosed before their seventh birthday. Although the participants did not represent a diverse socioeconomic range, the experiences among the three families were extremely diverse both in educational and life experiences.

Of the three participating families, two of the families had two fathers who were also considered to be on the spectrum but neither was officially diagnosed. The two men, representing two different families within the study, had two offspring, one male and one female. Each of the three families was married to opposite gender partners. The youngest couple had been married for 13 years by the time the study commenced, while the more seasoned couple had been married for more than 30 years. Of the three couples, I interviewed at least one of the couples, and for two of them I was able to schedule at least one interview with their partner. Each of the participants’ names and their family members’ names has been replaced with pseudonyms.

Table 3.1 Participant and Family Profiles

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Participant</strong></td>
<td>Oscar Olsen</td>
<td>Cathy Cape</td>
<td>Sam Smith</td>
</tr>
<tr>
<td><strong>Spouse</strong></td>
<td>*Olivia Olsen</td>
<td>**Christopher Cape</td>
<td>Sally Smith</td>
</tr>
<tr>
<td><strong>Child with Autism</strong></td>
<td>Owen</td>
<td>Candace</td>
<td>Stephen</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>7</td>
<td>30</td>
<td>23</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>2nd grade</td>
<td>Master’s Degree</td>
<td>Undergraduate</td>
</tr>
<tr>
<td><strong>Child #2</strong></td>
<td>Olga</td>
<td>Cane</td>
<td>Seth</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>5</td>
<td>Deceased</td>
<td>21</td>
</tr>
</tbody>
</table>
Oscar Olsen

Oscar was one of the four primary participants in my study and a professor at the local state University. Married to Olivia Olsen, together they have raised two children Owen and Olga. Owen, their oldest child, was diagnosed before the age of four and has had specialized training to help him navigate social communication. Olga did not present any autistic characteristics or other disabilities at the time of the study.

Oscar, of European decent, grew up in a small town in the Midwest. He was the son of a widow who remarried. Oscar’s biological father passed away when he was a young boy. He was the first in his family to pursue higher education. Although he had strong support from his family to pursue his goals, he always felt that his parents never understood him as an individual. His step-father eventually told him that we was surprised that he was able to accomplish what he had in school and his career.

As a young child, Oscar began reading prior to entering kindergarten and considered himself to be on the autism spectrum. He felt that he is not “far on the spectrum”, meaning that he considered himself to be high functioning. He described his way of being as a result of his brain being wired differently. Oscar considered himself to be a long-range planner while each plan being based on one target goal at a time. Oscar enjoyed his occupation, and had found great success in his career.

Oscar was conscientious of his imprint on the environment and did not eat meat for reasons of convenience and health. He enjoyed spending time with his family and self-time.
Oscar considered himself to be a perfectionist and only attempted things that are hard or perceived by others as extremely difficult. He lived by the notion that failing at something is only permitted once. Oscar and his wife lived a frugal lifestyle. Oscar did not subscribe to the notion that he had a disability. Instead, he felt that he was really good at many areas and not so talented in other areas. Oscar had won numerous distinctions as a teacher and researcher prior to this study.

*Cathy Cape*

Cathy, the second participant I interviewed, was married to Chris Cape, both of whom were employed by the University. Cathy was an administrator and Chris was faculty at their college. Together they raised two children, Candace and Cane. Earlier in her career she was recognized for her scholarly accomplishments and she reported to be very pleased with her overall career trajectory. Of European decent, she was raised in with in working middle class and described her father as a very smart man who was very handy around the house. He enjoyed building and fixing things and was known as the community handyman. She was not sure how “smart” her mother was because, in those days, as she recalls, it was difficult for women to demonstrate academic intelligence. Her mother was a homemaker who did not have the opportunity to pursue a profession. It was common expectation for women, including her, to graduate from high school, get married and nine months later, to have a child.

Cathy excelled in academics and she referred to herself as the “Pollyanna”, suggesting she was a reserved and obedient young girl who did not cause her parents trouble. Conversely, she described her brother as a “delinquent” who struggled in many aspects of his life. She thought that her brother never received the appropriate support in school, as he was thought to have a learning disability. Cathy attended an elite private college on the West coast but
remembered her parents not playing a role in her academics. It was not until much later in her adult life that she realized how much her father was proud of her accomplishments. She believed that his lack of participation in her academics was mostly due to both of her parents being somewhat intimidated by her academic accolades. Nonetheless, she always felt supported by her family.

Chris, her husband, was a respected faculty member and regarded as a lead researcher in his field. Cathy referred to him as a “high-status male” due to his professional stature which likely included his earning potential, impact on the field, and respect among his colleagues and friends. Cathy suggested that Chris is a classic case of an adult who had never been diagnosed with Asperger’s syndrome exhibiting many of the characteristics. According to her, he denied such a claim but she believed that he felt badly about “passing” on similar characteristics to his daughter.

Although never documented formally, she believed that Chris’ father exhibited similar Asperger’s-like characteristics but because he was a successful professional himself, these characteristics were ignored or his hyper-commitment to his profession was considered to be a sign of “commitment” rather than a disability. For both Chris and his father, it was likely to be a case of two professional men who excelled in their work and were given more leniencies when it came to odd behaviors. Cathy suggested that because their daughter does not have the “good” parts of Asperger’s syndrome, the fact that she had a diagnosed learning disability, and because she is a female, her giftedness was overshadowed by her negative aspects, resulting in more challenges in her career, family life, and her social relationships.

When asked about her son, she sighed and said, “…oh, such a sad story.” Cane, their second born, showed early signs of giftedness being able to read by the age of three. He was
larger, stronger, and faster when compared to his older sister. He excelled in sports, academics, and art as he progressed in school. He was considered to be very social and got along well with his peers. Cane went on to be a ranked chess player and received press for his winnings, often resulting in cash prizes. At an early age, Cane suffered from anxiety, depression, and attempted to commit suicide several times in his young life. He received support from his family and received therapy throughout his youth and adolescence. Eventually, Cane committed suicide as a young adult.

Sam and Sally Smith

Sam and Sally were the third and fourth participants whom I interviewed. Both Sam and Sally were born and raised on the west coast of the United States, whose grandparents immigrated from Japan. Sam described his family history in the following way,

Our parents were of the generation that was trying to "assimilate"
but yet were discriminated by being placed in relocation [Japanese internment] camps during WWII. From our parents’ generation as well as our grandparents, we have learned … about good work ethics by working hard and become adaptable to our situation/environment. We try to teach our children, even Stephen with his limitations, these work ethics, especially being adaptable.

[Sam]

Sam first attended community college and then transferred to a local prestigious public University where he received two advanced degrees in science. Sally met Sam while enrolled at the same University and they have been married for more than twenty years. Both described their
families as being a strong unit and appreciated the importance of being supportive of one another. The notion, “family came first” came up several times throughout the interviews.

Both considered themselves to be “OCD” although these references of being obsessed with important topics were made with a ‘tongue and cheek’ tone when referenced in the interviews. They used this popular culture term to describe their “drive” to be successful in many aspects of their lives. Their drive was also critical for their professional career, which allowed them to pursue professional degrees in science related fields. They spent approximately three years dating and then three more years married without children. They commented on how this time prior to having children allowed them to get to know each other as a couple. The Smiths also felt that the family unit was the most important priority in their lives. They worked hard to instill this belief with their two boys. They felt competition was a healthy process in the real world, but when it came to the family, it is important to be there for each other and to support one another along the way. Both felt that their children had the capacity to be successful in all aspects of their life and both want the best for their children. They also referred to their sense of drive when they described their philosophy on how they raised their children.

Sam and Sally both believed it was the parent’s responsibility to research and find the most appropriate services based on their child’s needs. Although they would welcome suggestions and recommendations, they found that many professionals in both medicine and education are not in tuned with the realities of autism. As a result, they took it upon themselves to investigate and use their own resources to meet their child’s needs.

Sam felt that he wanted his children to be competitive in academics and in the job market. Sally tended to be the planner in the family. She provided more organization to the family affairs and events but relied on Sam to manage the household finances. Both were
informal and social in their interactions and were pleasant to interact with. Sam expressed resentment and/or got frustrated when he heard professionals make assumptions about the potential of his son who had autism. He felt that most people underestimated his son’s potential.

**Child with Autism**

Although the children in this study were not the primary participants, it became obvious during my interactions with the parents that I might also have the opportunity to hear their child’s unique perspective as well. Of the three families, only one of the children requested to meet me. All of the participants had an official diagnosis of Autism and according to their parents; all three children had Asperger syndrome characteristics. All three children were reported to have at least one other known co-existing condition such as obsessive compulsive disorder (OCD), anxiety, depression, dyslexia, and processing deficit disorder. Although it was clear that medications were part of the regular regimen for two of the three families, it was not a major point of discussion during the interviews. Sam and Sally directly addressed the use of medications, but made a family decision to use other, non-medicine interventions to reach similar outcomes.

All of the children were genetic offspring of the parents, therefore were ethnically related as well. All of the children attended school, two of whom had already graduated from high school, one child attended public school while another attended a private, specialized school for the gifted and learning disabilities. The youngest child in the study attended a public school with a specialized integrated program that provided social communication curriculum and other appropriate services. Two of the three children attended school in the southwest while the third graduated from a high school in the southern part of the United States.
Owen

Owen was diagnosed in his elementary school years. At the time of the study, Owen was seven years of age and attended a public school that supported students diagnosed with autism. An evaluation was pursued because Olivia, his mother, noticed that he was regressing in his language. He came out on the “socially autistic side”, meaning it was difficult for him to engage in meaningful ways with peers. At an early age, Owen demonstrated strong interests in specific topics, one of them being the recycling process. Prior to age four, he had already acquired extensive background knowledge in recycling. Conversely, by the age of four he still had not been potty trained. After two years of reading books on potty training techniques and trying different approaches it occurred to Oscar that if Owen understood the logic behind using the toilet over the diaper he might be convinced that a diaper was not only an inconvenience but it was environmentally unfriendly. After a long, detailed discussion of how a dirty diaper was considered to be a pollutant compared to the alternative toilet option, Oscar, his father, convinced Owen to use the toilet. The very next day, Owen went up to his father and told him, “I don’t need a diaper anymore, Dad.” And from that point forth, he used the toilet.

Candace

According to her mother, from a very early age Candace had a lively sense of humor but struggled in large academic and social settings. After receiving the official diagnosis of autism and a reading disorder, Cathy, her mother, moved Candace into a specialized school where she eventually learned how to read. In her new school, the classrooms were smaller and the teachers had more training on how to work with children who were gifted with disabilities.

Candace showed an affinity towards learning Spanish as a second language. When she was in high school, she participated in a study abroad program where she traveled to South
America where she participated in her first cultural exchange. She enjoyed it and excelled at learning Spanish. Since high school, Candace has traveled extensively throughout the world, mostly in Spanish speaking countries. After receiving her first Master’s degree, she pursued a second in Education. Her goal was to become a Spanish teacher but did not pass her student teaching component. Nonetheless, Candace continued with her travels and often found herself extending her stays for months at a time, in some cases staying abroad for approximately one year. During her travels she would submit her resume to private high schools applying for teaching positions. She eventually found a niche for herself at several schools as an English as a second language teacher.

Stephen

Stephen was diagnosed with autism at the age of four and a half. The evaluation process took place as a result of his parents, Sam and Sally, observing that he was behind in reading by several grades and that he could not tolerate loud noises and would hide in the bathroom of his preschool. Stephen was described as a kind and bright young man. They were very proud of his accomplishments in school and they felt he had grown significantly, particularly in the areas of self-advocacy. Although Stephen had experienced decoding and reading comprehension difficulties throughout his educational career he had benefitted from tutoring and academic support provided to him by his parents throughout his educational career. It was common practice for the Smith family to spend three to five hours per night on homework during middle and high school. During college, even during the time of the interviews, he and his parents would spend approximately two hours of reading the assigned text together to ensure comprehension. According to his father, Stephen was a slow reader but once he was able to “get it”, he was able
to understand and apply that knowledge. Often times, Stephen surprised his family with random background knowledge on specific topics and his sense of humor.

During a recent family vacation to Europe, they visited a medieval museum. To Sam’s astonishment, Stephen recited facts about all the various types of body armor and weapons specific to time periods and roles of the people. Sam was surprised because he was not sure when or where he had learned so much about such a specific topic.

Data Collection Strategies

Negotiating Entry

My study proposal was approved by the Institutional Review Board requiring me to provide a disclosure statement to all participants. I provided each participant both an electronic and paper copy of the disclosure letter, which outlined the potential risks involved and the demand of the commitment (see appendix). With this formal process in place, it allowed me to negotiate permission into their lives, to hear their story, and to access events and settings only privileged members of their community or family might access. Each separate interaction and event afforded me the opportunity to earn their respect and build rapport with them and their families.

Data Collection

My data collection approach focused primarily on the coordination and facilitation of in-depth interviews, along with the collection of select artifacts from the families. The interviews were conducted in the spirit of ethnographic conversations, allowing for both the participant and myself to have a free flowing conversation using pre-determined prompts. To start off, I scheduled three interviews per family, the first focusing on the backstory of the participant, child and immediate family. The second interview focused on the present situations and the currently daily happenings of the family. The third interview allowed the participant to reflect on the two
prior discussions and to bring meaning to the stories and experiences shared along the way (Seidman, 2006). Each of the first three interviews were scheduled approximately 3-7 days within each other, allowing the participant to process the prior interview and to relate already told stories to new ones. After the first round of in-depth interviews had taken place for each of the participants, a significant amount of time had passed before I established contact with them. During that time I transcribed audio recordings of the interviews, listened and read the transcriptions several times over. I also used this time to continue to read new material either recommended to me or found in organic searches.

After this phase, I reached out to the participants for a second round of interactions, providing them with a copy of the transcripts and following up with supplemental questions that I had prioritized as a result of me going through the data. This second round of interactions led to greater insights for some, while for others it brought closure to a process that was somewhat time consuming and emotionally taxing.

During this process I learned that it was extremely important to keep an on-going log on interactions between to help me manage the many interactions I had with the participants. My data collection plan allowed me to interact with the parents but I found myself making modifications along the way in the process. For instance, I started off with scheduling three interviews with each parent, but I realized that although the partner of that parent was willing to be interviewed, it would have been very difficult to schedule three more interviews for that individual partly due to their lack of investment in the project, but also because time with me, might be time away from their normal day-to-day family affairs. One spouse of a participant was willing to meet with me but between the emotional commitment to talk about her son with autism and selling and buying a new house was simply too much for her to commit to. As a
result of her limited schedule and her emotional state, I opted not to pursue a time to interview her but let her know that if she would ever like to sit down with me or share a story that I would make myself available. Another family had just as much interested in being interviewed but had much less of an emotional charge to their son’s experience. Because their time was limited as well, I ended up scheduling three interviews for that family but the first two were with the father and the third was with the mother. Again, ideally, I would have had a total of six interviews with each family, but this would have been extremely taxing for the families because of their busy schedules.

In total, I interviewed three families, ten interviews with five parents and one unrecorded interview with one of the children. I recorded approximately 15 hours of interviews during a span of six months.

*Interviews*

As an active interviewer (Holstein & Gubrium, 1995), I engaged in a process with the participant that would allow us to construct meaning together as we explored the topics during the interview sessions. Interviews were conversational in nature and I attempted to arrive at a mutual understanding of the participants’ explanation of the discussed phenomenon. After completing the first round of interviews, which included a set of three interviews, I followed up with each participant with a copy of the interview transcripts. The first round of interviews were semi-structured, in-depth interviews that resembled a modified version of Irving Seidman’s (2006) three interview process, where each interview focused on a theme to be discussed. The goals for each of the three interviews follow:

1. Find out as much as possible about the context of her/his life leading up to her/his present.
2. Focus on concrete details of their lived experiences in the area of study

3. Reflect on meaning by placing emphasis on intellectual and emotional connection between participant’s work and life.

By providing this structure, along with the printed questions in advance, it allowed for the participants to focus less of the question itself and more on the stories and meaning of the experience.

The second round of interviews took place in a much less formal setting and were a direct result of me following up with the transcripts and scheduling the second round of observations. As I spent more time with the participants, the more stories, insights and connections were made between me and the participant. This co-constructing of understanding was a desirable outcome and was welcomed. I incorporated participant choice into every aspect of my research, including during interviews and observations. For instance, we met at convenient locations in town or on the University campus that was convenient for them. I also asked where they would prefer that I observe them, if at all.

Interviews took place in person and via email. All of the interviews in the first round were conducted face-to-face and recorded using a digital device. The audio format was converted into an MP3 file format and submitted for third party transcription. Each audio was transcribed in its entirety. Transcripts were shared with the participants to ensure the accuracy of the words spoken but also to provide the participant with an opportunity to elaborate on the spirit of the response or to share a related story that would further illustrate the experience.

Most of the interview questions in the second round were conducted either in less structure, often social settings, but also via email threads, or over the phone. Because of the authentic social interactions and less formal settings, many of the second round interviews were
not digitally recorded. Instead, in these situations, I recorded questions and responses in a note book that held my field notes and other writing I had gathered throughout the study. I later typed these notes and incorporated them in the larger data set for analysis. In this notebook, I also provided a greater context of the setting, described verbal and facial expressions, and wrote down quotes that were uttered. Particularly in the second round of interviews, my observations guided follow-up questions and directly informed my understanding of the responses.

Although they were formally structured statements, I used my interpersonal skills to ask the question and to keep the participant focused on the intent of the question. I found that using eye contact, without staring, and fluctuating my voice at appropriate times, as well as several other non-verbal techniques provided just the right amount of variance during interviews to keep the conversation flowing and not to get hung up on the formal aspects of the written questions and prompts. Below are examples of questions and prompts I used in the first round of interviews. To reference the complete protocol used, see Appendix I.

1. Tell me about your son/daughter.

2. Tell me about your life up until now, specifically about how it relates to your role as a parent with a child who has autism and go back as far as possible within our time frame of 90 minutes.

3. Tell me as much as possible about yourself related to your role as a wife/husband, partner, parent, community member and how it relates to having a child with autism.
   a. For professional/educator: professional, career, educator, researcher, advisor, teacher.
Below are examples of follow-up questions that were asked either via email or during the participant observation sessions.

1. “According to the transcript (see attached, p. 5) you mentioned that you have a family member who you and other called odd. In your opinion, and knowing what you know now about autism, what is your understanding of how autism manifests in your family?”

2. “I see that your son is interacting nicely with your students, tell me about a turning point in his life where he went from being more socially awkward to getting where he is today…”

There were several benefits to having on-going interactions with participants. One of these benefits is certainly that the communication led to a natural and continual flow for follow-up questions for both me and the participants. It helped me establish and maintain strong relationships over a long period of time and provided a sense of comfort and confidence to both of us to allow for candid conversations, particularly for topics that had been charged with high levels of emotion often times, over a span of many years for the families and children.

Artifacts

I asked each participant to select a few artifacts that they felt would be ideal to either provide a general context for their child and own personal experience. I also let the participants know that they could share educational documents such as psycho-educational evaluations or medical evaluations that further documented their family’s experience with autism. I encouraged families to think about items that would provide context to their unique point of view, which may include personal journal entries, photos, artwork and so on.

It was also important for me to keep in mind that all of my participants were seasoned professionals and faculty on a University campus which meant that, in addition to their already
busy family and social lives, they had very demanding schedules. Due to this detail, I also
realized that they may simply not have enough time or set it as a priority to sift through old
documents and archived boxes in their homes to provide me with such items. Knowing that, I
was very flexible and did not try to inconvenience the families. For some, the items may have
been too personal and they were simply unwilling to share such artifacts.

For one of the families, the daughter who was autistic expressed interest in meeting me
and ultimately sharing several documents that I was able to incorporate in the larger data set. She
shared a personal journal she kept when she was in grade school and her full evaluation of her
diagnosis. For these documents and the many others collected from the families, I scanned and
took digital pictures of each item, returning the original and providing a digital copy back to the
participant and the family. When applicable, I have included copies of these artifacts in this
dissertation for the reader to view the data first-hand.

Reciprocity

Going into this research project it was very apparent that I would be asking quite a bit
from each family as the stories they were about to share with me were not only very personal but
rooted in deep emotions, some pleasant, but many ripe with frustration, anger and downright
pain. Because I went into the project with this understanding I attempted, and I believe I was
successful, in making each participant feel welcomed and respected at each juncture of the
partnership. For instance, when a family shed a tear during a particular painful experience, I
provided tissue and asked if they would like to pause or stop the interview. For those who
wanted to continue, we took the time that was needed to recuperate emotions and then
proceeded. For those who opted to talk around the subject, I respectfully made note and did not
broach the subject until they felt comfortable to do so on their own.
I did not provide monetary compensation to participants but I did express appreciation to the participants in various forms, both verbally but also by small gestures such as thank you emails and hand written notes thanking them for their participation. As with any highly debated topic, many of my colleagues and those close to me did express their thoughts and opinions about autism but I chose to not include those opinions and input into my study. Although valuable insights and perspectives, the intent of this study was to focus on the family’s point of view, particularly the parents who have or are raising young children diagnosed with autism. The following section will highlight the strategies I used for data analysis.

**Data Analysis Strategies**

The following steps (Marshall & Rossman, 1999), provide a broad overview of my approach. First, I organized the data. Second, I generated categories, themes and identified patterns within the data. Third, I coded the data. Next, I tested my understandings of the emerging data by doing member checks. Fifth, I searched for alternative explanations in the literature. Lastly, I wrote the dissertation.

The process presented above is important because it helped me stay on track and bring order to what was already an overwhelming process. Though the steps above are presented in a chronological order for this report, it is important for the reader to realize that narrative research is a cyclical and recursive process that requires the researcher to move through the above steps outside of the order presented, similar to the way a thread weaves through tapestry – weaving through and back, moving forward, yet going back to specific points to close the research loop (Benner, 1985; Dyson & Genishi, 2005; Lawrence-Lightfoot & Hoffman Davis, 1997). In this case, the weaving took place, for example, between in-depth interviews and reading relevant research articles. For instance, when a parent made a statement about their understanding of the onset of autism, I found myself reading articles on the etiology of autism. Perhaps the research
topics could be considered peripheral, at best, to my research topic but I felt that in order for me to contextualize their statement, I wanted to better understand the medical community’s understanding of where autism is believed to come from and other aspects of its origin. Another example of the process being more cyclical than linear is that even after identifying codes within my data set, I found myself going back to redefine those codes and in some cases recoding sections of data due to an observation and/or insight made during my participant observations. After observing new patterns of behavior by the participants, rereading the transcripts, and reviewing the literature, it helped me identify alternative explanations of the same phenomenon.

As part of the ongoing, inductive process, I instituted a post-interview routine which helped to identify important issues brought up by the parents and to flesh out the data (Seidman, 2006). To do this, I reviewed my notes, added to my original notes and identified areas of importance for the participants. Parents tended to share similar issues and topics, therefore allowing me to observe themes across the several interview sessions amongst different participating families. This often resulted in the formation of follow-up questions and new questions that could be incorporated into future discussions with the parents. After each interview, I jotted down post-interview notes and listed to the audio file.

My transcription process involved three steps. First, I listened to the audio file listening for general topics. At each topic I found significant, I logged it by typing the general point the parent was making, while cuing it with a minute marker on the document. By doing this, it allowed me to become more familiar with the data prior to its full transcription. It also allowed me to make additional connections to the data that I had missed due to my focus on the participant during the actual interview. After completing this process for each interview, I submitted the audio files to a Web-based transcription company for a more thorough
transcription. Once I received the transcripts, I listened to each audio file once more while following along on the transcript. Next, for member check purposes and also to stay connected to the participants, I shared the transcript with the participating family. This process often led to several follow-up opportunities both via email and also in-person. Some participants took the time to expand on thought, make amendments to their statements and in some cases, invited me to sit down with them again or to observe them in a setting.

My process in composing the data analysis chapter was twofold. First, I read over the data sets to gain an understanding of the lived experiences of families with children who have been diagnosed with autism. To do this I prioritized two data sets, my field notes and my interview transcriptions. My field notes consisted of handwritten entries, then later typed versions, of accounts I observed firsthand. I used the MS Word application to highlight, insert comments, underline and to assign codes (Woodgate, Ateah, & Secco, 2008).

**Diagram 3.2 Single Participant Case Study Process to Gain Understanding**

(Woodgate, Ateah, & Secco, 2008)

Once I had a greater understanding of the data and specific data points that allowed me to illustrate parental understanding of their child’s and family’s experience with autism, I began the process to map out the data analysis chapter.
Next, to determine parental understanding of autism, particularly as it related to the child’s educational experience, both inside and outside the classroom, I used my field note entries and transcriptions to dig deeper case-by-case.

**Diagram 3.3 Multiple Participant Case Study Process to Gain Understanding**

(Woodgate, Ateah, & Secco, 2008)

While doing so, I “listened” to parents’ words, paying close attention to their examples, illustrations and connections to previous lived experiences. As Carrie Snow writes in her dissertation, “The practice of ‘listening’ required several close readings of the data in an effort to identify the ideas and issues that the [participants] found to bear meaning and significance in their lives” (Snow, 2010, p. 124). I created separate files for each participant’s raw data and scanned artifacts all as the process to help manage the data.

I found that when listening to the data, I was making a conscious effort to think about the data at the same time I was reading and/or hearing it. Essentially, I made myself be more aware of complimentary narratives, alternative ways of thinking about the utterances and behaviors, which helped refine my skill of “listening” to the data. By immersing myself into the data, layer after layer, I kept my eyes open for possible themes that surfaced in the data. As I encountered what I thought was meaningful, I assigned a mark which referenced a particular aspect of the
data. I used bold-facing, italics, and highlighting with various colors to indicate specific meanings to the themes within the data.

By the end of this process, I ended up with massive amounts of data that was identified as significant in some way. The next step involved me going through it again to prioritize the data and assign another layer of significance so that I could begin to distill the most meaningful data for the report (Miles & Huberman, 1994). Once I identified a set of tentative themes, they were refined and redefined until they represented the spirit of the parents’ responses (Taylor & Bogdan, 1998).

Diagram 3.4 Capturing the Spirit of Participant Responses (Lower Left)

![Diagram 3.4](image)

(Seidman, 2006; Taylor & Bogdan, 1998)

Diagram 3.5 Interconnectedness of Participant Stories (Upper Right)

Next, excerpts from the parents’ interviews were sorted and organized into these themes. It was common for a single quote from a parent to fit into one or multiple themes (Myers, Mackintosh, & Goin-Kochel, 2009). Lastly, the themes were organized into “higher-order” clusters which allowed me to unify several themes based on their context and a greater meaning (Myers, Mackintosh, & Goin-Kochel, 2009).
Ultimately, my goal was to identify new spaces in the tapestry, while keeping in mind that the tapestry, when its pieces together, provided a more complete picture of the case (Dyson & Genishi, 2005; Lawrence-Lightfoot & Hoffman Davis, 1997). It is in these holistic illustrations that the on-going, recursive process described above for qualitative ethnographic research that my insights began to surface and take shape for the report.

Presentation of the Findings

Each family’s life story was encapsulated within a brief profile highlighting its qualities and distinct experiences. I used a profile for each family to feature the background history and unique experiences from that participant, allowing greater insight and understanding. The profiles were also used as a brief reference to the participants’ perspective and life stories. The unique qualities I observed during this involved the different approaches participants approached the research process (i.e., interview and observational settings), variance in family structure (i.e., living arrangements and number of family members), knowledge of disability (i.e., severity of disability(ies) and known genealogical connections to autism) and educational experiences (i.e., levels of child’s educational level, teacher/school feedback). The data sources allowed me to
gain greater understanding in the parents’ participating styles, issues raised of having a child with autism and their evolving sense of identity as a parent, spouse, community member and friend.

The data is presented in various forms such as quotations, field note excerpts, interview excerpts, detailed descriptions of events and phenomenon and the accumulation of educational artifacts. When possible, I provided visual representations of the artifacts. Items such as photographs and journal entries were scanned to allow the reader to incorporate my interpretation into theirs, perhaps developing new interpretations based on the data I have provided.

Limitations of the Study

As Heath (1983) illustrated in her seminal piece, *Ways with Words*, there are many benefits when conducting qualitative research. Perhaps the most substantial benefit is the ability of the researcher to bring meaning to lived experiences as they are happening. By choosing this approach I made a cognizant decision to respect the natural life experiences of the participants as they were playing out. Although my study is not an ethnography, I do employ ethnographic techniques. By doing so, I was able to identify and highlight details of the participant’s story and provide a vehicle for them to become the central point of focus, which allowed for a deep understanding of the phenomenon. When pursuing this process, I felt as if I was holding in my hands hundreds of pieces of cloth while a voice inside me was saying, “Go ahead, put the pieces together. They shared their story with you because they felt their experience as a parent, coupled with their child’s experience, were worth sharing with others.”

As a researcher, “putting the pieces together” was where much of the pleasure came from because I viewed it as a puzzle and my analytical thoughts begin. I was challenged in ways that
made me grow as a trained analyst. I was forced to think in logical sequence with methodical bits and pieces. The challenge became so real that if I did not complete the task, I would have failed. Failure would simply not be an option for me as a professional. Simultaneously, while my mind was searching for the right fit for the pieces of the puzzle, I was also thinking about how these pieces of the puzzle actually represented the real emotions, thoughts, feelings, and physical manifestations of humans, now friends, who took the time out of their busy life schedules to share a sliver of their very personal lives. I soon realized that it was an honor to have been given the opportunity to have these pieces of the puzzle at my fingertips. Once that realization took place, a sense of responsibility weighed heavily on me and at times was so overwhelming that I found myself stagnant, in awe and not sure how to proceed.

What I just described above is a snippet of my reaction to this overall process of conducting ethnographic research. Josselson (1993) points out that qualitative research, in general, lends itself to achieving a wholeness of a particular phenomenon. By focusing on rich data, going deep into the participant’s story, a level of richness is achieved, getting that much closer to what is referred to as “holism” (Josselson, 1993).

After a certain number of interactions, time spent with each other, I noticed there was a level of trust built between myself and the participants. This was also true as I spent more time with the data itself. I felt more comfortable with the data and I began to trust it, just as the participants grew trust in me and my intentions. I wrote this dissertation in a way so that the reader could not only gain a unique perspective of this phenomenon, but also trust that I, as a researcher, did due diligence to the process, respected the people involved, their story and in turn could trust the narrative and interpretation provided, a concept referred to as “trustworthiness” (Tierney & Lincoln, 1997). As much as I would like the reader to trust my own interpretation
and ideas, I also expect the reader to build off of this trust to formulate their own interpretations and inform their current understanding of similar phenomenon.

In order to understand the limitations of this study it is helpful to realize how trust is built with all aspects of the research and how that trust is connected to concepts such as what is “true” and the notion of “Truth”. My goal for this project was to pursue an understanding of the diverse representations of what it was like for parents to have a child with autism. To accomplish this, it was important for me to understand participants’ divergent ways of thinking and behaving, which eventually led me to write descriptions of these understandings. At times, parents dispelled myths that are so often portrayed in the media. I also observed that there were instances when participants reinforced misunderstandings of autism. My intent was not for me to suggest that each of these families’ experiences were the “Truth”, in the objective sense. Instead, I wanted to share that the stories the families did share are true for them and their personal understanding of how they approached life with a child with autism.

I realize that my biases as a researcher were completely interwoven into the “fabric” of this project. As much as I believe this adds value to my understanding, I also realize this can be perceived as a limitation of the study, particularly the personal relationships I developed over time with each of the families. If at all, my preconceived notions may have provided a barrier in the analysis and/or interpretation process, when presented with new or existing data. Conversely, I would have liked to believe that the strong bonds I formed with the families allowed me to contextualize the family’s situation to gain greater understanding to particular aspects of their familial and educational experiences that otherwise would not have been accomplished. When taking this perspective, such strong bonds with the families added to the richness of the project.
As a full-time employee and middle management of a University academic support program that specializes in college students with disabilities, opportunities were both afforded and limited to me. As a result of my professional commitments, my busy work schedule limited my time and potential interactions with participants. I also had limited access of financial resources, compared to a researcher with educational or research grants to support such an endeavor (Marshall & Rossman, 1999). Conversely, as a respected member of the University community, I found that I had greater access and perceived credibility to other professionals on campus. As a result of my professional status, my participants tended to step forward after hearing about it from colleagues and were willing to share their personal story. This process saved time, as a result of close proximity to one another’s offices on campus. Due to my financial constraints as well as a relatively short timeline for my project, a typical one year ethnography was shortened to a six month ethnographic-like study. Due to such a short period of time, I believe I was not able to explore the many nuances of the participants’ stories. That said, I felt that the depth and detail I was able to describe was valid because the data was derived from its setting and it was authentic to the participant (Marshall & Rossman, 1999).

As a result of my particular approach to the topic of autism, particularly my methodological strategies, the ability to generalize findings is not only limited but in many ways contradictory to the purpose of the study itself. It is important to note that each of the participants were highly educated with advanced degrees in philosophy, psychology, engineering, chemistry, and pharmacology. Each one, in their own right, have very well established professional careers, many of whom are highly respected, leading scholars at one time in their respective fields. Due to the small scale, case study format, I gained insight into topics such as disability, trust, culture, gender, ethnicity, fairness, spirituality, and love. Essentialist tendencies such as objective Truth
and Positivism (Ferguson, Ferguson, & Taylor, 1992) are able to be discussed and analyzed in what would normally be considered to be a homogenous group. For example, because each of the participants had a Ph.D. or terminal degree in their respective fields, the reader might assume that concepts of success and achievement would be directly related to financial means and resourcefulness, which they might be. But one of the outcomes of this study was to show that even a population that might have been categorized as homogeneous due to their academic background, were in fact, a set of very diverse living experiences that shape who they are, how they raised their children, and for the sake of this project how they managed the day-to-day responsibilities of having a child diagnosed with autism. In essence this study is best understood when viewed as an opportunity to hear with clarity the participants’ distinct voices and their unique perspective on the topic (Biklen & Burke, 2006; Josselson, 1993).

As a final note to the interpretive process, it is important for the reader to know that this study represents a finished product but at the same time it represents a dialogue that is ongoing, not only in the literature but also for me, a researcher, and the involved participants. Due to my commitment to the field as a researcher and my role as an administrator for an academic support learning center who serves students with autism, the conversations I had for this study are only part of my overall experience with this topic. My intention is to gain a greater understanding and share it but at the same time I wish not to depict this phenomenon as something that was “discovered” (Denzin & Lincoln, 2003). As Denzin and Lincoln and others point out, it is critical for me, as a researcher, to embrace my own biases and do my best to understand my own history so that there is a clear delineation, when possible, between the understanding I brought to the participants’ story and the part of the story that is provided by my own history (Ferguson, L, & Taylor, 1992; Denzin & Lincoln, 2003). Lastly, to increase trustworthiness at every level and at
each milestone of the project, I conducted frequent member checks to verify the truthfulness of the narrative (Tierney & Lincoln, 1997). By eliciting the above procedures, which included a high degree of diligence, meticulous detail, and generous amounts of flexibility, I am confident that the data and analysis presented in this report was organized and delivered in a respectful way to the participants while meeting the rigorous expectations of the academic community.
IV – DATA ANALYSIS: “I Wouldn’t Change Anything…”

Yeah, there’s no doubt I’d do it again, just like going to school, I went to school longer than most people do. Would I do it again? In a heartbeat. I wouldn’t change anything, because you just have to do which you have to do in life. I think it was for the better, we’ll see. Maybe thirty years from now that I can say something about that. [laughs] .[Sam]

The narratives of the families who participated in my study provided insight into their personal experience when raising a child diagnosed with autism. The realities of autism for parents in this study is that a duality of emotions and feelings existed throughout the process of raising their child. Fleishmann (2004) captured this duality of emotions by identifying several competing emotions for parents such as experiencing “shock and guilt” soon after the diagnosis of autism but then experiencing a “sense of relief” as the parent gained greater understanding of their child and autism (p.38). Cashin (2004) also documented this phenomenon when he described how “simple pleasures…lead to big rewards” and how “patience is born from frustration” (p. 169). Below is a table of several other emotions and feelings that exist within the literature and that were also present in my study.

**Table 4.1. Duality of Autism**

<table>
<thead>
<tr>
<th>Odd but amusing situations</th>
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<tbody>
<tr>
<td>Shock and guilt with delayed relief and joy</td>
</tr>
<tr>
<td>Always a bright side to difficult situations</td>
</tr>
<tr>
<td>Welcome opportunity while dwelling on missed opportunity</td>
</tr>
<tr>
<td>Parents are not victims, they are daring mountain climbers</td>
</tr>
<tr>
<td>Simple pleasures lead to big rewards</td>
</tr>
<tr>
<td>Patience is born from frustration</td>
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</tbody>
</table>
Hopes and dreams at birth and fears and worries after diagnosis

(Fleischmann, 2004; Cashin, 2004; Fong, Wilgosh, & Sobsey, 1993)

Using Myers et al (2009) as a model for organizing the data, the following chapter is organized into five thematic clusters, each of which organized by two sections, challenges and strategies. The challenges represent the difficult and frustrating themes of having a child diagnosed with autism. The strategies represent the approaches and techniques used by the parents to address, push through, and overcome the challenges. The first cluster titled, managing the diagnosis process, includes statements from parents as they describe what it was like to observe odd behaviors in their child prior to diagnosis with, in some cases, limited knowledge of autism. This cluster also describes the parents’ experiences post-diagnosis, particularly as they navigated education and health care systems. The second cluster titled, child’s behavioral and educational needs, includes statements describing a parental perspective on their child’s social skills and academic needs. The third cluster titled, impact on parent’s well-being, work, and lives, provides insight into how these three families found meaning when raising their child with autism. The fourth cluster titled, impact on family as a whole, illustrates how having a sibling, father, and relatives with autistic characteristics has shaped the participants’ perspective on raising their own child. The fifth and final cluster titled, full integration into society, provides examples of how parents described how important it was for them to ensure that their child was exposed to various life experiences so that their child could become an independent adult in academic, social, and professional settings.

In addition to providing excerpts from the participant interviews, I present the existing literature as I introduce the themes, showing how my study’s results overlaps with the literature and where my study addresses possible gaps in the literature.
Although the literature is limited with regards to documenting the lived experiences of parents of children with autism, I was able to identify several studies (Cashin, 2004; DeGrace, 2004; Glass, 2001; Gray D. E., 1993; Gray D. E., 1994; Gray D. E., 2002; Woodgate, Ateah, & Secco, 2008). Overall, my data aligns with the literature, particularly as it relates to the diagnosis process (Hoogsteen & Woodgate, 2013a; Sen & Yurtserver, 2007; Midence & O'Neill, 1999), unsupportive and ineffective institutional systems (Hoogsteen & Woodgate, 2013a; Gray D. E., 2002; Woodgate, Ateah, & Secco, 2008; Hoogsteen & Woodgate, 2013b), the need for self-time as a parent (Mackey & Goddard, 2006; Vickers & Parris, 2005; Scorgie & Sobsey, 2000), and societies lack of understanding of what it means to have a child with autism (Hoogsteen & Woodgate, 2013a; Scorgie & Sobsey, 2000; Ray, 2002; Glass, 2001; Gray D. E., 2002).

Conversely, there were also aspects of my data that were not found in the literature. For instance, all three of the sets of parents who participated in my study mentioned that they encountered a point in their child’s life that they were not able to relate with him/her. Eventually, this inability to understand their child’s perspective was frustrating and caused high levels of stress.

Moreover, there were few articles that documented the positive aspects of having a child with autism (Hoogsteen & Woodgate, 2013a; Hoogsteen & Woodgate, 2013b; Scorgie & Sobsey, 2000; Fleischmann, 2004; Myers, Mackintosh, & Goin-Kochel, 2009). The parents who participated in my study recognized the many challenges (realities), but it was also very easy for them to identify the positive aspects of having a child on the autism spectrum, such as their own growth as a parent and positively impacting their professional skillsets. Additionally, while my participants expressed a fear for the future they also did everything in their power as a parent to prepare their child to seek career preparation, healthy social relationships, and appropriate romantic partners.
Table 4.2. Clusters and Themes of Parent Responses

<table>
<thead>
<tr>
<th>Cluster 1 – Managing the Diagnostic Process</th>
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<tbody>
<tr>
<td>Challenges</td>
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<tr>
<td>• Feelings after diagnosis</td>
</tr>
<tr>
<td>• Ineffective systems</td>
</tr>
<tr>
<td>Strategies</td>
</tr>
<tr>
<td>• Coming to terms</td>
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<tr>
<td>• Taking ownership as a parent</td>
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<th>Cluster 2 – Child’s behavioral and educational needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenges</td>
</tr>
<tr>
<td>• Lack of knowledge among educators</td>
</tr>
<tr>
<td>• Peers and play</td>
</tr>
<tr>
<td>• Academic skills</td>
</tr>
<tr>
<td>• Child’s lack of awareness</td>
</tr>
<tr>
<td>Strategies</td>
</tr>
<tr>
<td>• Trial and error</td>
</tr>
<tr>
<td>• Explicit teaching from the parents</td>
</tr>
<tr>
<td>• Awareness of stressors</td>
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<tr>
<td>• Creating an educational plan</td>
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</tbody>
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<th>Cluster 3 – Impact on parent’s well-being, work, and lives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenges</td>
</tr>
<tr>
<td>• Disconnect from child</td>
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</tbody>
</table>
• Feeling overwhelmed

Strategies

• Gaining perspective

• Having a plan

Cluster 4 – Impact on family as a whole, siblings, and extended family

Challenges

• Blame and guilt

• Economics of autism

• Comparing child to parents, siblings, and extended family members

Strategies

• Time with child and family unit

• Find strengths and positive mindset

• “It takes a village”

Cluster 5 – Full Integration into Society

Challenges

• Society’s limitations

• Future fears

Strategies

• Enhancing understanding

• Being optimistic

Parenting a child diagnosed with autism can be a very gratifying experience especially if at the end of the long journey desired outcomes are achieved and a parent can look back and say...
to herself, “it was tough but my daughter and I are better for it today and she will be ready for whatever comes tomorrow” [Sally]. As gratifying as that may be in the long run, no one has the ability to look into the future to know exactly how it will all turn out. For that reason, many parents might find themselves feeling trapped in the present, leading to frustration and increased anxiety (Myers, Mackintosh, & Goin-Kochel, 2009). For many parents, this is a very daunting and frustrating time because of the work required to keep the family fully functional at any given moment. In other words, the time required and the neck break-like pace at which things move for parents who have children with special needs often limits the scope of vision for a parent. Simply put, looking into the future can be a luxury many cannot afford.

According to those who participated in this study, their day-to-day reality was not only filled with a great deal of responsibility and activity, but they also experienced a range of emotions, shifting from very gratifying thoughts and feelings to, in a moment’s notice, frustration, anxiety, doubt, and blame. Parenting a child with autism is a lifelong vow to patience, trial and error, and most importantly unconditional love. These attributes, along with several specific strategic approaches, can lead to a great deal of success. However, evidenced by my participants, alongside the many successes still remained a level of uncertainty in life that never seemed to reside, no matter what phase they were in during the process. Each step along the long journey provided demands of their time, patience as a loving parent, and aspirations for the future.

**Cluster 1 – Managing the Diagnosis Process**

Prior to diagnosis, it was common for my participants to have made several observations regarding their child’s behaviors, thinking to themselves, *That’s odd, why is she doing that?* When reflecting upon that moment, often times years later, it became obvious to them they had
observed early signs that their child had autistic characteristics. Due to their lack of awareness and knowledge of autism at the time, they did not make the immediate connection and did not pursue a formal assessment of their child. It is well documented in the literature that although parents had noticed signs, perhaps even recognizable autistic characteristics, parents tended to be in a state of denial because they were afraid of what might come of it (Midence & O'Neill, 1999; Hoogsteen & Woodgate, 2013a; Sen & Yurtserver, 2007). Soon after diagnosis, it was common for parents to experience mixed feelings, which included shock, guilt, and anger (Fleischmann, 2004; Fong, Wilgosh, & Sobsey, 1993; Koydemir & Tosun, 2009). Sen and Yurtsever (2007) pointed out that parents in their study expressed feelings of shock, denial, suffering, and depression soon after they received the official diagnosis. Midence and O’Neill (1999) documented similar findings of guilt and despair. Although the timeframe for acceptance was unique to each family, it was a common theme among these studies, including my data, that parents eventually reached a level of acceptance, which eventually proved to be a milestone in the parents developmental process (Koydemir & Tosun, 2009; Fleischmann, 2004). Fleischmann (2004) described it as a “turning point” and illustrated this epiphany with a quote from a parent, “Like a flash in my mind, the word ‘autism’ came to me… I approached the teacher the next day at school and she confronted her fears” (p.39). After parents had reached this turning point in their own development, it was common for them to experience greater levels of acceptance and confidence (Oprea & Stan, 2012). Similar to my participants, parents felt more empowered as time passed and as they became more aware on their child’s needs. In many cases, the fact that they knew what to call it and that there were other families and children with similar needs, allowed them to get passed the mourning process of losing a child and to “get into action”. A parent in Fleischmann’s (2004) study explained, “I went outside and threw up. Then I started my
“battle plan” (p.39). Learning the intricacies and being informed of the facts of autism helped parents gain greater understanding of their role but most importantly it led to understanding their child (Midence & O'Neill, 1999; Koydemir & Tosun, 2009).

Although evident in my study, I did not find a study that explained how parents attempted to find the genetic connection of autism to themselves, the other parent, or to a family member. In my study it was clear that the mother or father reflected on the origin of their child’s autism. The parents were afraid that their child “got autism” from them, as if it was a contracted disease. My participants understood that there were likely to be genetic connections, but the fact remained that much of the science behind autism was unavailable, which created uncertainty, curiosity, and in some cases feelings of blame, guilt, and shame (Midence & O'Neill, 1999). It may be important to note that all three of my participants are highly educated in science-based fields with doctoral level degrees in areas of pharmacy, psychology, and chemical engineering. Their educational and professional backgrounds likely have impacted their overall knowledge and understanding of the science behind autism. They admitted that they would often read peer-reviewed journal articles on the topic to stay current with the etiology and best practices. Perhaps, as a result of their background knowledge and their willingness to seek scientific answers reduced, but not erased, the notion of blame and guilt as it related to their child’s diagnosis.

Challenges

*Something was different.* Each of the families noticed something odd or different about their child early in his/her development. For the Olsen family, they had already noticed that pattern-like behaviors and routines were essential to limiting the “melt-downs” they experienced with Owen. Owen tended to get excited and nervous about minor changes in the day’s schedule.
What they considered to be a minor change of plans was equivalent to an Earth-shaking event, impacting Owen emotionally and physiologically. Minor modifications of the day’s schedule would induce anxious behavior and sometimes resulting in undesirable repetitive behaviors. For Owen, this often meant sucking on his t-shirt. His father, Oscar, noted:

I could tell when he was really nervous because half his shirt would be wet…Another very atypical day, this goes back to Owen’s preschool and pre-autism diagnosis. We’d always prepped him well in advance. We recognized pretty early on that anything out of routine was very disconcerting for him. [Oscar]

When describing his son’s anxiety, Oscar used words such as “vibrating in his seat” as a way to illustrate how his son’s energy levels increased as a result of changes to his already established routine. Oscar described his behaviors as if Owen was a character in an animated television episode.

Similar, to the Olsen family, the Cape family saw signs that their daughter had difficulty with changes in her routine, but the signs first manifested in different ways. In Cathy’s situation she saw her daughter, Candace, struggle academically, particularly in reading. What made it particularly stressful was that when Candace was challenged in reading and in related academic tasks, her anxiety would increase significantly and eventually turn into tantrums that were both physically and emotionally exhausting for her and those around. Since these types of behaviors were rare, especially early in Candace’s development as a child, Cathy remembers being particularly worried and started to pay more attention to these behaviors.

Then when she started pre-kindergarten, I guess when she was four, we were working on identifying the letters and things, and
pre-reading things. It just wasn't connecting with her at all. We began to think that there was something a little off. Then, when she started kindergarten it really became even more noticeable, and it was kind [of interesting] to even think back exactly what kinds of things [had happened that I never paid much attention to].

She's left-handed, so sometimes you’d think, ‘well left-handed kids are just slower with motor development’. But she just would scribble, and most of the other kids were able to sort of write their name, and she couldn't at all. She didn’t get any of the pre-reading stuff. It wasn't that she seemed slow. One of the things that was interesting, she had a very good sense of humor, and was very good at word play. We didn't have a sense that she wasn't smart, it seemed to be that there was something a little off… it was clear she just wasn't getting anything, particularly the reading stuff. I guess the other thing that was a little off, was she would get very, very frustrated and throw temper tantrums. Normally she was very mellow, so this was not a kid that you would anticipate these just violent, temper tantrums and just completely losing control.

[Cathy]

The Smith family noticed there were differences with their child, Stephen, relatively early in his development.
Our son was born in 1989, in June. As far as we know it was a normal pregnancy. All vital signs were normal, neurological exams normal, gross neurological exams, as far as I know. He had a normal development up until the time he was about three and a half, when we noticed that he had a difficult time putting words together and expressing himself. The only way we could titrate that at the time was, we'd hear other kids that he'd play with, and he also was a little bit shy. [Sam]

As Stephen developed into a young boy, his parents noticed that he continued to have difficulty with language, mostly with literal and figurative speech. Sam, Stephen’s father, recalled when returning from a Boy Scout camping weekend the Scoutmaster yelled out, “Let’s move out!” Stephen turned to ask his father, aloud in front of his peers, “What are we moving out?” At first, Sam admitted that these types of reactions from Stephen were a little embarrassing as a father but over time they, he and the family as a whole, learned not to think of them as embarrassing moments, but instead of reframing them as his strengths.

Prior to diagnosis, each of the families had already observed oddities but they had not yet learned enough and had not “connected enough dots” to propel them into the next phase of discovery. In this case, that next major step was diagnosis.

*Feelings after diagnosis.* Each of the participants had their own unique approach to understand and process their child’s diagnosis. Although there was a sense of relief that science had provided what they considered to be an answer to their most basic question -- What is it? -- it was evident that at least two out of three parents experienced a sense of shame, blame and even devastation when they learned about the details of the official diagnosis.
One of the families had a slightly different experience because the father (Oscar Olsen) a, professor of chemical engineering, had eventually came to realization that he, himself, was a classic case of an adult who was undiagnosed with Asperger’s syndrome. In his case, he felt at ease with his own peculiar behaviors, obsessions, and unique approaches to the world. He later explained that after one of our interviews he asked his wife her opinion about his behaviors as an adult. He learned the following:

Olga and I talked about it on Sunday. I asked her, ‘how do you view Owen and I being similar or different?’ She said, ‘You both have your obsessions.’ I didn't ask her what she meant, but I can infer some of them.

We had some students over and Owen brought out his hamster. His hamster is dead, cremated in a box. The students said, ‘Oh. I'm sorry. When did your hamster die?’ Owen goes, "December 7th, 2012." The precision that's there.

I was kind of making fun of myself since I've been talking to you a little bit. I've not been restraining myself like I normally would. Normally, I would email a student and I'll say, ‘I'll see you tomorrow.’ Now, I'm having fun with my details and numbers and I'm like, ‘I'll see you in roughly 12 hours and 37 minutes.’ [Oscar]

Oscar believed that he and his son shared many characteristics, particularly the way they think about numbers and time. Because of these similarities, Oscar described a sense of camaraderie with his son, and his wife confirmed this feeling.
Conversely Cathy, Sam, and Sally; who did not consider themselves to be on the autism spectrum; had different reactions to their child’s diagnosis.

He [Chris, Cathy’s husband] feels bad because he knows he annoys me and inconveniences me. He probably feels bad because he thinks he passed this [autism] on to Candace. On the other hand, depression runs on my side of the family. I've had several relatives who committed suicide. If we're going to play that game, I have to take responsibility for my genetic contribution for our son.

I don't know if that bothers him or not. We don't really talk about that…I used to say that Chris had to take them [to the orthodontist] because crooked teeth came from his side of the family, and no one in my family had crooked teeth. At some point I decided that was really not that cute, I should probably not push that line. [laughs]…Candace has some things, ways of doing things that are exactly like a grandmother. You see these, and sometimes it's not appearance, it's really mannerisms and things that are clearly genetic and you can't help but appreciate that. [Cathy]

Each of the families made direct connections to their child’s diagnosis and their family genetics. Although “blame” was not placed on the genetic contributions from Sam, he linked autism back to a family member and recalls the diagnosis was particularly difficult for him as a father.
When he first started preschool at the age of three, he would hide in the bathrooms. He could not tolerate loud noises, but we just kind of attributed it to the fact that maybe he was just a little bit slower in development…For example, I think my wife has some family members who have Asperger's. This guy [Sally’s cousin] likes to chase storms, but at the expense of being a very, very shy and withdrawn person. He comes here twice a year to go, or once a year in the summertime to go chase monsoons. He does it by himself. He doesn't really care about socialization skills, things of that nature…[after the diagnosis, we] found that he (Stephen) was two standard deviations below the normal development of another child at his age, four and a half. Which was actually pretty devastating, because we knew that he now had some type of speech and language deficiency. [Sam]

The participants in my study consistently reported feelings of devastation and blame when it came to their feelings immediately after diagnosis. Even when negative feelings were not the primary outcome, all of the families relied on the science of genetics to explain their feelings and awareness.

*Ineffective systems.* As Oscar was reflecting on his and his wife’s experience prior to and after the diagnosis, he realized that one of the main reasons why his parents did not seek a diagnosis for him when he was a child was due to the simple fact that in those days there was not the awareness that we now have. Moreover, he lived in a rural area which meant that population density was low resulting in fewer resources in the vicinity of where they lived. By living so
much farther from their neighbors and community resources, it made it less likely to have a physician and other practitioners close and affordable enough to access. He explained:

Even today, yeah. The population's so small. [Our city] has what, one doctor? It took us a year and a quarter to get in with her for [Owen]. We have 800,000 people. Where my parents live, to get 800,000 people, you'd probably have to take 27 counties. A geographic area of probably 5,000 square miles...Something on that order to get to one doctor. Yeah, it just wouldn't work… It was going to cost $2,000 and it would take at least six months before we found out. We worked with our medical insurance, we finally found the one doctor who did the evaluation, took over a year of waiting to get [Owen] in and then the diagnosis came back and that's when he was now eligible [for services at his elementary school]. [Oscar]

Cathy concurred as she, too, found it challenging to navigate the educational system:

The teachers really had no sense. The school just kept saying, ‘Oh, you're up-tight, type A parents.’ I kept saying, ‘No, there's something not really OK here.’ [Cathy]

Sam recalled a specific time when they were struggling to get the appropriate services set up for him in high school.

When our son was 5 years old, which was 18 years ago, there really wasn't very much known about autism. It was something that we knew existed, but as far as development and education
strategies and teaching strategies were concerned, there really wasn't anything out there. There was one example of a local high school here…that had a special education component. Most of the teachers were good, but a lot of the kids were not very collegial, I guess [that] is the best way to put it. They would tease my son and call him a freak. They weren't very respectful of his disability or himself. I think that frustrated him a lot. It turned out that even the principal was somewhat less than stellar. I don't really want to go into a whole lot of details of that. You probably don't want to hear it anyway. [Sam]

Overall the families suggested that the reality of autism today is that resources are still not student-centered, parent-friendly, or sometimes downright inaccessible. It was particularly surprising and frustrating for all of the parents when they realized that key professionals in educational settings lacked knowledge and understanding to their child’s needs. Lastly, each of them noted that availability of services were sparse at best, limited in terms of best practices in intervention and support, and associated costs were expensive, particularly to those without insurance.

**Strategies**

The following sections describe the mindset and approaches parents used to offset the many challenges they faced regarding the diagnosis process. Parents found that by accepting their child’s diagnosis they were able to reach an important milestone in their own development. By taking ownership of their child’s autism it propelled them into a state of action, which provided them the confidence to explain their child’s needs to professionals and others.
Coming to terms. At some point, for each of these families, they had come to a realization that “enough was enough.” They had either been told to “just relax” or “don’t worry” too many times and after the Nth time of being told s/he will grow out of it and everything will be fine, they eventually took it upon themselves to seek a formal diagnosis. After observing the oddities of their child, and in all cases comparing them to family members with similar peculiarities, they admitted that something was different. The next logical step was to actually find out what it was about their child that made her/him different.

If I think about Owen, access was so hard. Olivia knew there is something wrong - different, not wrong, different with Owen when he went non-verbal. I had noticed that eventually because of my interactions with him at home, day after day but she [Olivia] noticed instantly. Then, as she was trying to explore why and was pushing for more information she contacted the autism alliance…[Oscar]

Sam recalled a similar moment when he and Sally finally made the next big step,

When he first started preschool at the age of three, he would hide in the bathrooms. He could not tolerate loud noises, but we just kind of attributed it to the fact that maybe he was just a little bit slower in development. Finally, at the age of four and a half, almost four and a half, we actually had a speech and language evaluation done, a cognitive evaluation, and found that he was two standard deviations below the normal development of another child at his age, four and a half. [Sam]
Cathy recalled the moment that led them to the formal evaluation phase. She mentioned that Candace was a unique case because she had both Asperger’s syndrome and a reading disability, which made things even more complicated. By admitting something was different it opened the doors for greater understanding as a parent but she soon realized that it would also lead to immediate action on her part, which led her to finding a school that better suited her learning needs. She immediately observed the difference in Candace’s performance.

Finally we paid to have her tested, and the diagnosis was Asperger's and learning disabilities. We transferred her, there was a very good school that specialized in learning disabilities, and there they had classes of 10 people, 10 students. She had a wonderful teacher, and we also had after school tutoring a lot. She finally learned how to read, but it was very, very difficult. She just couldn't get the connection. [Cathy]

_Taking ownership as a parent._ One of the most challenging realities for parents is the need to take ownership of their family needs while not placing the “blame” on themselves, their spouse, or others. These families realized early on in the process that by taking charge of the situation and by reducing the tendency to blame others, it allowed them to focus on the immediate needs of their child. Cathy recognized this can be very difficult for parents to avoid, particularly mothers.

It's funny, I feel pretty good about my parenting, even though I had a son that committed suicide and I have a daughter who can't take care of herself. I don't know why, but I don't feel like I'm to blame. Partly, our son was always telling me, ‘This has nothing to do with
you mom, this is me.’ It always sort of seemed that way. Kelly
doesn't seem to blame me, so somehow I've escaped the guilt that I
think a lot of mothers would have. I don't know why. [Cathy]

Sally referenced propaganda in the early days of autism where women were the
scapegoat for the origin of autism, which led to humiliation, greater frustration, and an overall
sense of shame. “Because back in the 60s, that's when they used the term ‘refrigerator moms’.
The moms were cold, that's why the kids ended up the way...”. In that same conversation, Sam
expanded on what it meant for him to take responsibility. By doing so, it allowed him to find the
needed resources to help his son be more successful in school and in life.

There's this whole transition. I think Stephen was born in this
transition period where they went from that trend to now
applied-behavioral analysis and all this other stuff. The fact of the
matter is that when you have a child, you have to do something
about it. You can take everybody's recommendation. You can do
colic lavages, you can do functional MRIs, which were in its
infancy stages. But the question is whether they work or not.
What's going to happen at the end of the day? The final
responsibility for that is us, is his parents. We chose to do what we
did with him.

Not bragging, not saying that it's the way that one should do it with
all their kids, but as far as I know, and as far as he is today at the
age of 23, and almost graduated from a university, I think it
worked. I think it worked pretty well, or at least as good as it could work. Of course the jury's never out till he's out and he has his own career and everything.

But as far as some of these interventions that were recommended, you have to make a decision. Some of them I thought were just like heresy, to tell you the truth. We chose to do what we did, and would we do it again? I think so. I think we'd do it again, the way we did it. Sometimes we were a little bit too strict with him, I'm sure I was. It's why he says, ‘Oh, Dad's too tough on me.’ But I think we got him to where he had to go so far. [Sam]

Sally contributed to this same conversation, this time addressing their professional knowledge of psychotropic medications and other intricacies of the medical field.

I think both of us, since we do have some experience in medicine and stuff like that, we tend to be more cautious. In fact, neither one of us prefer to use any medications if we don't have to. It's just working in the hospital and seeing how many patients are on umpteen-million medications and stuff like that, I go, ‘No. That's what causes problems.’ I think, and we didn't want to complicate things. We wanted to be able to work with him, and he's fine. Sometimes we wonder, ‘Well maybe he needs a little anti-depressant,’ but then we do other things. ‘Hey, Stephen, let's go to DQ [Dairy Queen] to go get an ice cream or something like
that.’ Or something more upbeat, or we go see a show, or something like that. ‘Oh, OK.’ Then he doesn't have to study and he's fine. He's fine with that. [Sally]

Sam summarizes he and his wife’s comments by suggesting that they are very proud of their approach as parents because they always kept the best interests of their son in mind and they wanted to keep things simple. Although it was important for each of the parents to seek complex, sometimes sophisticated evaluations and interventions, it was important for each of the families to simplify the process for their own understanding and for their child and family. They eventually realized that this “distilled” approach was also extremely helpful as they interacted with extended family members, friends, and community members. By educating themselves on the facts and complex nature of the situation, they were able to distill it for practice use, which contributed to a positive impact on their children’s lives. In doing so, these parents were also able to avoid bogus or ineffective treatments clinicians wanted to try. By taking control and ownership of the situation, they had no reason to blame others. In fact, by reframing their child’s autism to a positive aspect of life and even considering his autism as a gift, there was not a need to blame themselves or others.

**Cluster 2 – Child’s Behavioral and Educational Needs**

As families gained more confidence and the need for resources to support their child in his/her development, it was common for the parents to experience a high level of frustration with ineffective community agencies, institutions and practitioners (Gray D. E., 2002; Woodgate, Ateah, & Secco, 2008; Hoogsteen & Woodgate, 2013b; Myers, Mackintosh, & Goin-Kochel, 2009; Fleischmann, 2004; Fong, Wilgosh, & Sobsey, 1993). Parents found that they had to “fight” the system in order to get what they needed for their child. It was documented that even
when they were able to find appropriate services for their family, the practitioners were too busy with their case load and simply could not take the time to learn about the specific needs of their child. This was particularly disappointing for parents early on in the process because of their lack of knowledge and awareness (Hoogsteen & Woodgate, 2013b). When interviewing a parent in their study Fong and associates (1993) found that one parent was upset because the professional had claimed to have knowledge and expertise in working with children on the autism spectrum, but in fact did not. Their participant’s explained, “You don’t learn about autism out of a book. You learn about it in hands-on experience” (p. 110). It was common for parents, particularly those from rural areas to have met with a practitioner, such as a doctor, nurse or a specialist and not follow-up with them to see how their child was doing (Hoogsteen & Woodgate, 2013b). The literature pointed out that parents experienced a sense of worry and helplessness as they learned of the limited knowledge and support that there was among teachers, administrators, professionals, specialists and in the greater community (Fleischmann, 2004; Aylaz, Yilmaz, & Polat, 2012; Fong, Wilgosh, & Sobsey, 1993). Parents in my study used the word “drive” to capture what was needed in order to continuously fight the health and educational systems. When comparing drive with what was documented in the literature, I came up with the theme, “trial and error”.

Trial and error comes from the fact that parents did not have adequate and efficient means to access services. As a result, they had to try approaches and strategies on-the-fly until they found something that worked with their child. They used terms such as “ineffectiveness,” “frustration,” and “drive” to describe the ineptness and inaccessibility of the institutional systems. As they made their way “up to the front of the line” of the educational and health care systems they described their effort as needing to push through the many obstacles along the way.
in order to get the services they needed. During this fight, they had to advocate on behalf of their child, his/her needs, and articulate their questions and concerns as a parent. Moreover, once a parent experienced success in pushing through, then they had to do it all over again because it felt as if they had new challenges each day. As time went on for the families and as the needs evolved for their child, so too, did the need to access new health care and educational systems. Hoogsteen and Woodgate (2013b) reported that they found parents who were so desperate to get their child what they needed that they felt as if they were playing the roles of the teacher, tutors, and the therapists. Similar to what my participants reported, this led to increased levels of anxiety and exhaustion due to the amount of time needed to seek such interventions and resources. Similar to the results of my study, Cashin (2004) also found that parents’ frustration and worry grew as a result of them realizing that their child did not know what was best for them either. Although the trial and error process did yield some gains for both participants in my study and those documented in the literature, parents still found it frustrating because it felt like it was a guessing game that they would never be able to win because it felt as if they did not know how to help their child, their child did not know how to help themselves, and practitioners did not know how to help the child or family.

Although parents were still faced with many challenges such as behavioral outbursts, tantrums, and obsessive behavior, parents did find ways to help their child behave more appropriately in social settings, advance educationally, and gain greater independence with self-care (Fong, Wilgosh, & Sobsey, 1993; Aylaz, Yilmaz, & Polat, 2012; Myers, Mackintosh, & Goin-Kochel, 2009). Fong and associates (1993) found, just as I did in my study, parents taught their children using reward systems, modifying the child’s environmental setting, and researching the best schools and service matches. In their study, Oprea and Stan (2012) found
that parents were greatly appreciative when they found compassionate and competent specialists who understood the needs of their child. They also found that parents in their study suggested that they would not have been as successful teaching their child how to behave if it were not for a collaborative effort between the family, schools, and therapists (Oprea & Stan, 2012).

Challenges

Lack of knowledge among educators. As time progressed, so did my participants' knowledge of autism. It became increasingly difficult for the participants of my study as time passed because they, as parents, noticed how autism was manifesting itself in the child’s life yet the teachers and other educators were not aware of what autism was, much less how to help their child be more successful in the classroom. For parents like Cathy, it was frustrating to learn that their own knowledge of autism had surpassed that of the teacher. Cathy explained her experience as her daughter, now an adult, attended in a University managed lab school.

We moved to Memphis when Candace was starting first grade, and she was in a lab school on campus, which was, I don't know where people get these crazy ideas. But in first grade they had a combined class, so there were 60 students and 3 teachers. But it was just a zoo, and she became very, very stressed. She was very anxious and cried every day. She didn't want to go to school, she had a stomach ache.

Since it was a lab school there were one way mirrors, so I spent a lot of time observing. It was just chaos, and you could tell she just couldn't deal with everything that was going on.
The teachers really had no sense. She was at the tables, and there's a little boy [with a similar sounding name] who was at the same table who was always in trouble. The teachers constantly were looking over and screaming, [his name], ‘stop that!’ And our Candace would just go like this [Cathy covered her ears and tucked her head], because she was a very well behaved child, I never yelled at her. I had to move her and everything, but it was clear she just wasn't getting anything, particularly the reading stuff. [Cathy]

Sam was especially disappointed to see that the leadership of his son’s school did not meet his expectations. During the interview, it was clear that Sam’s frustration was still fresh enough in his memory to elicit some anger, which led to not wanting to go into details about his opinion about the principal.

There was one example of a local high school…that had a Special Education component. Most of the teachers were good, but…it turned out that…the principal was somewhat less than stellar. I don't really want to go into a whole lot of details of that. You probably don't want to hear it anyway. [Sam]

Peers and Play. Each of my participants provided stories about how their child exhibited what they referred to as odd behavior during social settings at school and around peers. It was challenging for parents to witness this because just like most parents, they wanted their child to have the opportunity to form strong and healthy friendships. Oscar recalls what it was like for Owen when he was a toddler at the park.
I don’t think it’s all or nothing. I don’t think so. When I look at where my son was and where he is now. I can surmise that he is on the same kind of pathway [as me]. Maybe different, he’ll be different. When my son was all the way up to 3.5 [years of age], we would take him to the park and he would have a play date. The other kid would play and talk with his parents and us and Owen would sit there and play. And the other child would be sitting there next to him and play and Owen would not respond in any way at all.

Oscar continued to share stories about the various ways how Owen is different than other children. “Sometimes you’ll see him go off the pattern and you’ll see his friends get a little confused because Owen has just completely shifted topics. He was talking about one thing and now he has left far, far away. Maybe from my perspective I can see where he got there. They don’t stand a chance.” [Oscar]

Cathy remembered a time when it was awkward because as a young girl Candace was often the victim of bullying by other children. “She was always bullied. There was something just sort of off about her, personality wise. Junior high was really, really difficult. She still can't seem to do her hair, or any of the things that are important in junior high and high school life.” [Cathy]

With a similar experience, Sam recalled when his son Stephen was harassed by his peers which eventually led him to transferring to another school. “He did well academically but…a lot of the kids were not very collegial, I guess is the best way to put it. They would tease my son and call him a freak…call him stupid, and everything else. They weren't very respectful of his
disability or himself. I think that frustrated him a lot. We didn't like that, but we were going to continue on.” [Sam]

_Academic Skills._ For both Sam and Cathy, it was clear that their child also struggled with reading, writing, and speech, perhaps aspects of autism and co-occurring learning differences. Ultimately, these academic challenges made it even more difficult because it meant that the parents had to find resources to help their child find success in and outside of the classroom, particularly if they wanted their child to advance through middle school, high school, and into college.

Stephen’s development was slow. His teachers noticed this, that his cognitive development was slow, his ability to read was slow. Often times, when he read, he would always want to say the words ‘and’ and ‘the.’ But we actually just kind of proceeded with his schooling. Until about the fifth grade, and then we were told that his reading was way below the norm. As a matter of fact, in the fifth grade, he had the reading level of a first grader. He had the math level of a second grader. [Sam]

Cathy remembers when her low academic skills transferred over to a real-world setting. Her academic skill gaps were even more pronounced because her younger brother, age three at the time, was already reading, which led to greater concern for Cathy and even more frustration for Candace.

We walked down using the map, and turned down our street. The three year old [Cane] immediately got what we were doing, and
Candace, she'd get mad because she couldn't figure out the concept. There were lots of cognitive things like that. She still can't cut well with scissors, but most of primary school is cutting, [laughs] and she never could learn to cut with left-handed scissors, and all that. [Cathy]

Child’s lack of awareness. The next two excerpts illustrate how it was difficult for parents to witness the child’s lack of emotional response to crisis or awareness to his/her surroundings. It reminded the parents that their child seemed to lack a fundamental skill that would prove to be important in navigating social situations. Cathy explained what it was like for her in a professional gathering, which eventually required her to intervene,

First of all, she's not at all shy. She's, in fact, kind of too outgoing. She doesn't have any restraints, so if we're having people over, she butts into the conversation. She talks too much, she doesn't get cues that maybe she should shut up and let someone else talk. She's very social, but not always a great way. She doesn't have any sense of hierarchy.

I remember at Memphis [University], we had an event for the new President, at our house, and she was in high school. I think everyone else was a little respectful, and yes sir, and she just acts like this is her uncle. This was for the women on campus group, and the point was for them to meet the President. Not for Candace. So I kind of had to drag her away. She's not very good at it, she doesn't avoid social interaction, and she can come on too strong. I
think she forces herself into situations that are new, like this travel. I think it's kind of a self-improvement thing. I know it's hard for her, I know it's stressful, but she just kind of does it anyway.

[Cathy]

Oscar recalled a time when Owen saw his mother crouched over on the kitchen floor and did not display what he described as a normal response. Oscar explained the situation and provided insight as to why his son reacted the way he did.

I know that he did not respond emotionally at all in some places where other kids really would have. My wife described that this is where she realized that he was probably not cognitively the average. She was sobbing on the floor with post-partum depression on the floor in the kitchen. Owen said ‘mom you’re crying.’ It was his observation. That was it. He walked out of the room. Most kids are not going to respond that way. They are going to be in tears and asking what’s going on. He just passed through. [Oscar]

Overall, the participants in this study were challenged in ways that impacted the child’s social relationships and academic achievement. By not having supportive and knowledgeable educators it created a sense of despair, which then led to frustration and greater levels of anxiety. The parents in this study felt that they had to take matters into their own hands and intervene academically and socially, which led to greater responsibility on the part of the parent to advocate for their child and their needs. The following strategies were used out of need, filling in
gaps where educators fell short and where the few books that had been written provided few answers.

**Strategies**

*Trial and error.* The more I listened to the families’ stories, the more I heard a sense of “tug-of-war” between themselves and the systems they attempted to access. For the most part, these systems were the health care and educational systems. On one hand, these were the very same institutions that were designed to provide the needed services, yet they seemed to be the same ones that were causing most of the difficulties. Some of these difficulties included the process to match the appropriate services to their child’s needs, to provide timely and accurate information, and to express positive and high expectations of long-term success. In response, the families found themselves feeling like they had to fight against the system, rather than simply accessing what was designed for the child’s needs. Once enrolled and accessing various types of services, they realized that clinicians’ and practitioners’ knowledge was limited and in some cases non-existent. As a result, they found themselves going through a process of trial and error to help their child and their family understand how to navigate the challenges they faced each day. In effect, parents tended to be trailblazers in their community and found themselves to be experts on what worked and what did not for their child.

Oscar recalls one example, early in Owen’s development, lack of routine caused havoc and undesired behavior from him. To avoid this, they learned to prepare Owen for days that were different than the rest, often weeks in advance, providing him with the time needed to process the change, ask questions, and “get ready” for that unique day.

And so Olivia had a dentist appointment scheduled on a Thursday and so one month before, we started saying to Owen, and he was
about three and a half, ‘Four Thursdays from now, Mom might not be here in the morning. She has a very early dentist appointment and she might not be back in time when you get up.’ We repeated that every other day and then in the three days before, we were repeating it to him. He got up first thing in the morning, I heard him run through the whole house, pull out a chair, looked out the front window and he said, ‘Did Mom walk to the dentist?’ I said, ‘Why?’ He said, ‘Our car is out front.’ So, even at three and a half, he was using fairly high level, I mean, that’s pretty deductive logic that you would not expect a three and a half-year old to have but he was aware that the state was going to be different and he went and confirmed visually. Ironically, Olivia was already back. She had driven but she had gone back to bed. We knew it was going to be an atypical day for him and we tried to prep him as much as possible so that he would not have a melt down and burst into tears and be upset if Olivia was not there. So, it would be literally the first morning she wasn’t in his whole life. [Oscar]

Sam shared related stories about how he and Sally found ways to overcome the gaps in services and knowledge among clinicians. According to Sam and Sally, there was another component to parenting a child with autism that was often over looked - learning by trial and error. They realized that some of the programs and services available in the community were not specific enough to their son’s unique needs. Instead of relying on just the formal programs at the schools and by clinicians, they ended up using strategies that they learned on their own, such as
taking turns, using breaks, and chunking material into manageable pieces. In Stephen’s case, he continued to use those strategies well into college.

We tried things out and if it worked great. If it didn't work we'd try something else…The other thing that we were concerned about at the time was our son's level of tolerance. What fifth grader studies three hours a night? Very few, very few. We didn't know, and this has existed to this day, what level of tolerance he would have for this type of thing. It's very, very stressful, for a fifth grader to study for three hours, just like it's stressful for a college student to study for five…Often times, what we'd have to do is, we'd have to try and figure out the best way to work with them. We would try to switch back and forth so that neither of our levels of frustration would show, although, there have been many times when we've been frustrated, not being able to explain things to him or to teach him something.

My wife is much more tolerant than I am. That's why he likes to work with her more than work with me. However, I work with him more. What we would do is, we would, sometimes, talk about what strategies would work. A lot of it was just very experimental.

[Sam]

Cathy recalled that her overall persistence as a mother helped Candace achieve a very important goal – earning her driver’s license. Her license represented so much more than a piece of plastic allowing her to be among the many drivers on the road. It represented another phase in
the development of their thirty year old daughter, who at some point would have needed to become independent enough to get herself to work and run errands without having to be shuttled by her parents. The resolve needed by both Candace and her parents was a true test. Their commitment to pushing through and staying committed to the ultimate goal of lifelong independence was obvious.

I guess the other main thing was when she was 14, we started with driving lessons. The driving school said, ‘she's never going to learn to drive, please don't bring her back’, and we kept changing driving schools till we'd gone through all of them, and it was just awful.

So, when we moved here, this time, you know she's 27. We started again. She finally made some progress, and it's actually easier to drive here than in Memphis. The way the left turns work is easier. So, and we always figure, we probably spent $40,000 on driving. Finally, when she was 30, she got her driver's license, which was a huge, huge step forward. [Cathy]

*Explicit teaching from parents.* The following set of excerpts illustrated how parents taught their child how to behave in social and educational settings. In all of the cases, the parent and child had received formal training from professionals in the field of how to reinforce desired behavior using behavior management plans. In turn, the parents used these strategies and incorporated them into the child’s routine. Because this level of parenting is time-consuming and ongoing, parents described feeling tired and overwhelmed with the number of times they found
themselves teaching their child how to behave, what would otherwise have been naturally acquired human behavior.

Yeah. [Candace] never got along with peers. I would spend a lot of time explaining to her, ‘Here's what I heard you say to Susie, and this is how it made Susie feel. When you do this, it puts them off.’ She wouldn't get it. She'd be resistant, and she would argue with me. But, over these many years, she's better able to. I've really noticed it a lot in the last couple years with her student teaching. Before, she did a lot of volunteer work with the schools because she was bilingual, and she would come home and just be so impatient and intolerant because the teacher didn't do something that she thought was right, or something. Now she'll sort of laugh about it...

Yeah, she's always struggled with [seeing other’s perspectives] and I spent a lot of time just explaining how the world looks to different people. It's always been the case that I'll tell her something and she'll resist, but then a week later you can tell she heard it. Whereas now, she can sort of acknowledge that she gets it without having to save face or digest it. [Cathy]

Sam found himself teaching his son ‘bad words’ in hopes that he would pick up on subtle but important uses of language either directed to him or in other social situations. Sam also points out that this type of explicit training can be challenging for parents with a child with autism because other parents do not have to worry about these types of things.
The thing that we have to remember is that all aspects of development for our child have to be learned behavior. For example, we have to teach our son [Stephen] how to swear. We have to teach him vernacular. As you can imagine, a child with autism often times cannot comprehend figures of speech or metaphor. We have to explain those figures of speech or metaphor to him. So that an extra component of his development that we have to teach.

He's in his fifth year of college now, and he's doing well. He's got about a 3.2 grade point average. He's doing well. He's in very, very good standing at the university. But we also have to focus on the other components of his development which most parents don't have to deal with in quote-unquote normal child development, and that is socialization skills and communication skills. [Sam]

Oscar provides details as to how he learned how to teach his child specific ways of being social and has witnessed successful outcomes.

[Owen] was trained to recognize patterns of conversation [in] Pre-School. We’d go and observe and drop him off. The teacher would be saying ‘Owen, see my mouth is moving right now. You hear words coming out of my mouth. That means you do not start talking. When I stop, you may ask if you can ask a question. If the other person starts talking, you don’t start talking, you wait.’ So,
he’s trained in these patterns of having an interaction. And now if you saw him yesterday when he had his two friends over, ironically, one of them was the kid that we used to take him to [the park] with that he used to ignore and now they are really good friends many years later. [Oscar]

_Awareness of stressors._ Oscar and Sam share insight into how it has been helpful for them as fathers to be aware of their son’s physiological reaction to stress. Oscar also pointed out that he and his son react similarly to excitement. He explained:

Another instance comes to mind that reminds me of Owen. When Owen gets very excited, he goes up on his toes. He primarily walks on his toes. I remember being in middle school, Seventh grade. I was walking down the blue hallway towards the stairs. The secretary came out and she knew my parents somehow and she said ‘oh, you’re going to be a sprinter, aren’t you?’ And I said ‘what do you mean?’ and she said ‘you’re walking up on your toes.’ I went on to be a sprinter. [Oscar]

Sam suggested that by being aware of what triggers his son’s stress he can better understand his son’s needs. By being in tune with his son in this way, he has greater understanding as to why Stephen behaved the way he did in specific situations.

For example, one thing that oftentimes we'll see is repetitive motions. I think. I'm not an authority here. [laughs] But this is what
I think I've seen. What I've read is that, for example, sometimes children with autism have a tendency to do this repetitive motion.

I see that in my son sometimes. The reason why he does that is actually to decompress and to relieve a stress component. From the time he was young, I mean he could swim from the time he was younger than three. But the one thing he always liked, even when he goes swimming in the ocean, when he goes swimming in a lake, he likes that constant bounce, that rhythm. One of the things he enjoys is bouncing on a ball, one of those Pilates balls, because he likes that rhythm.

Sometimes what he does is, when he has to decompress, he'll go into the back yard and he'll hop, because it makes him settle down. It just relieves anxiety. Sometimes he talks to himself. I can see him doing that. He's recounting a show or something. He's actually living it in his mind. I think you see that but in a much more severe way in cases of more severe autism, I think.

He's cried before, if he can't take it, although he doesn't cry very much. I don't know. I don't really know the answer to that. I just know how he deals with it. And that's why swimming was really, really good when he was in high school, because it kind of decreased the anxiety level. What else can I say? Just physical exercise helps quite a lot. [Sam]
Creating an educational plan. Once parents had a good understanding of their child’s educational needs it was common throughout all three participants for them to explain the importance of creating, modifying, and delivering on their child’s educational plan. Often times the plan would be a verbal agreement or discussion among the parents and child (when old enough) to determine goals for tutoring, school placement, and interacting with teachers/college instructors. Cathy talked about her conscious decision to move Candace and her son Cane to a better school that had smaller classroom ratios between teacher and pupil, greater understanding of learning differences, while being academically rigorous to help them prepare for high school and college. By making these decisions early on in the child’s life, Cathy explained that Candace eventually learned how to accept who she was as a person and found a great deal of success in her academic career, despite her ongoing challenges with reading, writing, and peer relations.

Then in Memphis, they had Magnet schools. The Memphis day schools are really pretty terrible, but these Magnet schools were good. You had to qualify to get into them, so she managed to score high enough on the standardized tests. She got through high school. She went to St. Olaf, I don't know if you know anything about St. Olaf in Minnesota…it's a really nice school. It's a Lutheran school. We're not religious, and she's kind of anti-religious, but it's kind of an old hippie place. They're really into peace and justice, and it's a very kind of accepting place. She visited a lot of schools, and she just really liked St. Olaf. It's just a nice atmosphere, and she did pretty well there…They didn't give grades, they did long reports. Her reports were always that she
didn't work well in groups, that she was stubborn. She tended to be judgmental, couldn't see other people's point of view. That's something that we worked on, and she will tell you...[that] she acknowledges that she's finally able to accept that. So, she was rigid and she always got into some dispute. They did a lot of group activities and projects, and it was very difficult for her. She majored in Spanish...She did a lot of international stuff in college, and later. [Cathy]

Sam elaborated extensively on Stephen’s journey starting in primary school all the way to current day, which is his junior year in college. He explained that he and his wife felt obligated to make the change because the school setting that his son was in was simply toxic. “After preschool, he attended a Montessori school, and we primarily put him in that school because they were. Sometimes kids get teased and ridiculed and we knew this school was very, very good at not allowing that. [Sam]

They transferred Stephen latter in his high school years because the bullying was getting out of control and the school’s administration was “less than stellar”.

He went to Green Tree High School, which was a new school. They just hired a new special education instructor, who was excellent as far as keeping an eye on Stephen. He was her prototype model, so to speak. He liked the school much, much better. Much, much better. The kids were much more accommodating with him. The teachers were much more accommodating. He had friends in the
school, and they all liked him. He was in the first graduating class in that school. His class was only 20 kids. He progressed to the point where he was the class valedictorian. He gave a speech in high school. By that time, he also got accepted to the University, because he wanted to go to college.

Sam further explained that he and Sally had an advantage because together they had a combined seven college degrees, three of which were terminal or professional degrees. This level of education and college experience afforded them great insight into the college process, curriculum, which eventually helped them create an educational plan for Stephen.

…we knew what it takes to go to college. What it takes to get good grades. What it takes to get in to professional school. What it takes to get into a good graduate school.

In a way, it helped us when it came our kid's time to go to college, and especially my older son, [Stephen]. We knew what the landscape was, even though I went to college, let's see...I finally got out when I was about 38, so 20 years ago, after my post doc. We knew what the landscape was about, and so it helped us as far as designing a program for our older son. [Sam]

In addition to having a great deal of college-knowledge, Sam and Sally also described the importance of reviewing and adjusting their plan as Stephen continued to make progress through his college career. They noticed that by the end of his freshman year, they had to adjust the plan. Sam explains,
Before he started college, though, we set up a plan where we would meet all of his professors, and we also had him enrolled in the [University’s support service for students with learning and attention challenges]…

But we knew he was having trouble comprehending the questions for exams, so what we decided to do was alter our strategy a little bit, whereby we would talk to the professors and have Stephen talk to the professors before the beginning of each semester, and we would outline to the professors that he could take his exams in the DRC, but often times he could not get anyone to clarify a question. The DRC could only read the question verbatim.

We would ask the professors if they would entertain the idea of giving him the tests in their office or having him start the exam with all of his peers in class and just walk to their office and give him the additional time because then he could get clarification of questions. It turns out that a professor is not obligated to give you extra time if you don't take the exam in the DRC, but everyone was willing to do that.

There was only one professor who wasn't willing to do that, but he's taken about 30 classes now, and 29 of them allowed it. And even the one who didn't, eventually just allowed him to take time in another room. That was very, very successful. [Sam]
In sum, the participants in my study explained the importance of being in tune with the behavioral and educational needs of their child. By experimenting with new strategies and techniques they eventually found what was successful and then shared it with one other. Moreover, by using the behavioral modification plans presented by the school and agency professionals, they were able to reinforce positive behavior and maximize their child’s good behavior in and around educational settings. It also proved to be important for parents in this study to be aware of what excites their child and what causes increased anxiety. Lastly, using educational plans such as choosing the most appropriate school setting, seeking academic support services, and teaching their child to articulate his/her needs to teachers, professors, and others proved to be critical for their child’s overall social and educational success.


Unlike the findings of my study, the literature documents examples of the parents’ loss of freedom (Fleischmann, 2004), less spontaneity, time, energy (Cashin, 2004), and greater stress and burnout (Koydemir & Tosun, 2009). Koydemir and Tosun (2009) point out the three aspects of stress and burnout their participants described. They acknowledged the presence of stress and burnout, identified the sources, and reflected on the coping strategies related to stress and burnout. In their study, mothers reported that exhaustion and being the primary care giver were the two major sources for causing burnout. Additionally, financial limitations and negative attitudes towards them and their child also played a significant role in deteriorating their source of energy (Koydemir & Tosun, 2009). Aylaz and associates (2012) also found that mothers tended to give more care to their child with autism, which directly impacted their overall psychological state, often resulting in depression and low energy. One parent from their study recalled, “…one night I had to drive him around from 01 till 04 in the morning, then I slept for 2-
3 hours and went to work” (p. 399). Cashin (2004) described how parents yearned for spontaneity and new and interesting conversations. Instead, parents were forced to be immersed in the world of autism, which lends itself to limited exposure to new things, routines, and conversations. Cashin (2004) wrote, “The lack of ability in abstraction and the literal interpretation of meaning of those with autism can mean the slow death of humor and teasing as forms of communication” (p. 167).

Most families reported that much of their lives as parents revolved almost exclusively around the children and battling burnout and fatigue was a real concern each day. Unlike the results to my study, parents did not feel they had sacrificed or missed out completely in life (Hoogsteen & Woodgate, 2013b). Although my participants suggested that they may have pursued specific professional tracks within their specific fields or would have traveled more, they considered those things to be significantly less important when looking at the bigger picture. The sentiment of, *I just did it because I had to…* was taken much more than, for instance, *I regret having missed so many career opportunities.*

Overall, parents also reported career related problems, spousal conflict, and social isolation as other aspects of their lives that presented challenges (Myers, Mackintosh, & Goin-Kochel, 2009; Koydemir & Tosun, 2009; Aylaz, Yilmaz, & Polat, 2012). More specifically, Aylaz and associates document how couples’ sexual lives are reduced or sometimes completely non-existent as a result of exhaustion and stress. One father explains his mixed emotions as it relates to sexual interaction between he and his wife, “Having an autistic child affected my sexual life very much, I always suppress my sexual appetite;…I also feel guilty;…my wife also influences this feeling of guilt in me; when I have an appetite for a coitus she mostly pushes me back and scorns me saying ‘how can you be so willing when our child is in this situation?’.”
Similar to the literature, my participants found that their relationship with their child matured into a very loving bond between parent and child over time. Aylaz and associates (2012) had parents say, “He’s everything in my world, I approach him with patience. I love him so much” (p.398). An overlap between my study and the articles also existed as it related to “being there for the family” and the need to set aside time for oneself as a parent. Mackey and Goddard (2006) documented several cases where parents felt like they were prioritizing the health and wellbeing of their child and family over their own. After time, they had realized that this sacrifice was detrimental to their long-term health and adjusted accordingly. Vickers and Parris (2005) reported similar findings when one of their parents suggested that their needs should not come last. In response to this new found awareness, many parents took the initiative to take better care of themselves and make time for themselves and their partner (Hoogsteen & Woodgate, 2013b; Mackey & Goddard, 2006; Vickers & Parris, 2005; Scorgie & Sobsey, 2000). Woodgate et al (2008) and Ray (2002) found that the parents who participated in their studies strived to find balance and promote healthy relationships to battle the extreme amount of time needed each day to care for their children and family. According to them, the parents did this by taking breaks to keep the energy levels high and allowing them to refill the “reserves”.

As a result of taking time for themselves and reinvesting into their relationship with their partner, families reported enriched lives amongst each other (Myers, Mackintosh, & Goin-Kochel, 2009) and a triumphant connection with their child (Cashin, 2004). As demonstrated in my study, parents were in awe of how successful their child had become. Fleischmann (2004) documented one parent who admitted, “[He] doesn’t know this but he inspires me every day” (p.40). That parent explained, as did my participants, how proud she was that her son was such a
great student but also a great teacher, teaching her the important things in life, such as love, patience, and perseverance.

Challenges

*Disconnect from child.* One of the most obvious challenges parents faced was the inability to relate to their child. Situations usually revolved around what would be considered by the parents to be common sense applications or activities that many of them took for granted because they, as a person without autism, could not relate to it. In Oscar’s situation, because he had his own personal insight into the world of autism, he found himself reinforcing what he considered positive behavior even though his wife found it extremely difficult to relate with their child, particularly as Owen learned to read.

When he was learning how to read this past year and over the summer, my wife would get really frustrated because what she would observe him saying all the right words and he’d get to a big word and he’d guess something that to me would be very plausible but she would say ‘Owen, you’re not even trying. You’re not even seeing it, you need to break it up.’ [But I knew] he does not read that way. [Oscar]

Cathy still struggles even though Candace is well into adulthood. There are “little things” that Candace should have learned by now but because she has not, they turn into “big things”, all of which are very frustrating to Cathy. She gets especially frustrated when she has to repeat things over and over again. It is this never-ending feeling that seems to frustrate Cathy the most. She explains:
I try, and I'm always torn between trying to change her behavior and just dealing with it. This is another silly example -- toilet paper. We've lived in this house for twelve years and it has these really nice, kind of fancy, toilet paper holders that have a flap that are seriated. If you put the toilet paper so it goes like that, then you tear it off. You put it on the other way, and you tear it off, you rip your knuckles. Now, I could just remove those, but they actually look kind of cool and I have three bathrooms -- it would be a production. I explained and I demonstrated, and after twelve years, she consistently does it backwards. Now, I just turn the toilet paper over, but every time I do it, I'm like, ‘Argh.’

I've demonstrated and I've thought, well, then I think...I don't know if you've studied memory, but one view of memory is you have a proposition and there's a tag attached that makes it negative. So maybe she's losing that tag, so I need to tell her positively instead of saying, ‘Don't do it this way, do it this way.

So I've tried strategies, but there's always this tension. Do I try to change these daily irritants? One day I'll say, ‘It doesn't matter.’ And then the other day, ‘If she does this one more time, I'm going to scream.’ So a lot of this is a function of what level of stress or fatigue I'm going through. [Cathy]
Feeling overwhelmed. A major component of having a child with autism is the complex and many moving parts of any given day and the needs associated with the child, family, and other external forces. Often times, it is easier for a spouse to “bow-out” for one reason or another. The reality is that the mere volume of decisions and the pace at which one must act can be overwhelming. For Cathy, it is particularly challenging because not only does she feel obligated to meet the needs of her daughter, but her husband’s Asperger’s-like characteristics are particularly challenging. Between her daughter’s needs and her husband’s, she feels that she has very little time for self, resulting in fewer hobbies or interests that she can pursue.

Well, this looks like something that came genetically from him [her husband]. He also gets very frustrated. I curse computers because I spend a lot of time doing tech support for him. He can't remember how to alphabetize his files. I kept saying...you just click over. He asks me this once a week, and he's very smart. He's very accomplished in philosophy, but he can't do anything. I didn't realize it when we got married, we were students. I hadn't seen him in a non-academic role, I had no idea how completely incompetent he is. He gets especially frustrated with Candace. The two of them have a very close relationship, but he often just has to bow-out and leave the room. He just isn't capable of the kind of patience, particularly when she gets hysterical.

She still gets very worked up. I was trying to think of what happened this week, some very minor thing. She gets hysterical, and she can't work through whatever the problem is. So he has
some difficulty. But he's [her husband] been very supportive, but I think he's left most of the decision-making to me. He does whatever needs to be done. He still can't ride in the car with her.

[laughs] [Cathy]

Strategies

*Gaining perspective.* In direct response to feeling disconnected to their child and in some cases their partner, parents found themselves taking the initiative to gain insight into their child’s perspective, asking the simple question, “What must it be like for them?” My participants exhibited a genuine interest to learn and understand what it was like for their family members to be going through this process as both an individual but also as a member of a family unit. Some of the strategies used to overcome these difficult situations included making themselves available to their family members and making time for themselves.

In Oscar’s case, because he had even greater insight into his son’s approach to reading, he reassured his son that he was on the right path to reading after a very frustrating homework session with his mother.

I don’t read by syllable, I read by length and the shape of the word and the context of the word. When I am reading if I were to see ‘in the United States population’, I would have guessed what population was by the shape and size and length of the word and where the high and low parts were. My son does the same thing. [I told him,]‘keep reading the way you are, I see what you’re doing. I’m comfortable with that. I’m not worried.’ It was just fascinating
seeing him because I didn’t know that he was reading that way, actually. [Oscar]

Cathy explained how she made herself available to her children at any point of the day, even if it meant that she would stay up until the early morning the following day. By using this approach she felt that she did a good job as a parent and that her family could rely on her on all aspects. She admitted that making herself available was sometimes exhausting. However, in the long run, it helped her accomplish her greater goal, which was family unity and a sense of pride as a mother and wife.

I worked hard to have good relationships with my kids. That's one of the things I always told them, ‘If you ever need to talk, it doesn't matter how busy or how late, we'll find the time.’ I used to get so exasperated. I had all evening and then I'd just be getting ready to go to bed and then Cane would come and say, ‘Can I talk to you?’ and I'd be up until 2:00. I felt good that he had believed me. Parents always say, ‘If you ever get in trouble and you need me to come pick you up, even if you've been drinking,’ and kids never believe that. I feel like I was pretty aware of what was going on in their lives. I was glad they were always willing to talk to me, even though sometimes you wish you could have silence. [Cathy]

Cathy explained that she continued to make the effort to reflect and gain insight on what seems to be very challenging tasks for her husband and daughter. Although the reality is that her husband and daughter are likely not going to understand some of what they refer to as “arbitrary rules”, she continues to practice patience and understanding in very challenging situations.
I mean, that's a good example of the other thing. I don't know if you're going to talk to my husband -- I think I told you he doesn't admit he's on the spectrum -- but he does the same thing. The refrigerator we've had for 12 years and every refrigerator I've ever had, it has a deli tray, it has vegetables and it has citrus. Those are different temperatures for a reason. Chris and Candace put things in the wrong place, so I explain, and they're labeled. ‘Look here, this tomato that you put in the meat, it's colder there. See, it froze. Now I have to throw it away. And see this meat that you put in the bottom? It wasn't cold enough, so it's rotten.’ I've explained it all, and both of them have said, ‘You have all these arbitrary rules.’ And I'm thinking, ‘the refrigerator is labeled. They're different products.’

It must be difficult if everything seems like just an arbitrary list of rules that people made up to make things complicated. And actually, we don't have a lot of rules at our house, it's pretty loose.

So there's that kind of thing where I try to explain. My husband still...I don't mean work the TV, do anything complicated, like turn it on or off. I've tried to explain the logic of, ‘Here's the remote.’ To him it's just an arbitrary sequence of things you do, and he doesn't see a connection between different functions.
So I try to explain that you're communicating. It needs to know whether you're talking to the cable, the TV set, or the DVD player. I guess because I get it from both of them, I appreciate that it must be hard to have to memorize all of these rules, when apparently there's not a scheme or anything in their head that corresponds to it. [Cathy]

Sally points out that one of the strategies she and Sam used was to make time for themselves as a couple. By doing so, they allowed themselves the time to reflect on their child’s needs and on their own. Perhaps the most beneficial aspect of this self-time is that they talk about other things completely unrelated to the family. By doing so, Sally suggests that it frees their minds from the reality of continuous hard work and dedication that is needed to keep their family moving forward.

I think that's one thing, at least what we try to do, is have time either in the morning or night, where it's just our time. That's usually walking the dog. That way, the family's not there and stuff. We just say whatever we say. It's outside, and the dog's not going to do anything anyway. I think that's our time, and I think that's important, especially with any child. Well it's not even a child with a disability, it's any child with a need. Being able to communicate and have our own time, so that it gives you time, weather it just be nonsense kind of a thing, or just even time to just ‘OK, how are we going to do this? How are we going to regroup?’ Plan of attack so to speak.
I think that helps us, as far as being able to just have our time.

That's probably true for any couple actually. If you have kids, sometimes you just need...give me five minutes away from the kids. Just talk about things and stuff. [Sally]

Having a plan. One of the struggles addressed above is that parents felt that there is a great deal to manage when a parent has a child with special needs. The sense of feeling overwhelmed can be very debilitating and cause parents to ‘spin their wheels’ leading to the inability to seek and provide the needed support for the child at that particular moment. To combat that feeling, the parents in this study broke down tasks into smaller pieces with the purpose to draft a plan. Often times these plans would be as a result of trial and error. For instance, they found out what worked the last time and incorporated that into the next time they encountered a similar situation. In some cases, a particular approach was learned and deemed successful so that parent shared that strategy with his/her spouse so s/he could incorporate it in the next time. In other cases, the original plan had been deemed outdated because the strategies used simply did not work anymore. The ability to devise a plan, as well as the flexibility to modify it proved, for these participants, to be a critical aspect of their interactions between spouses and as a family unit. The process of trial and error also led to the packaging of many small strategies into a more comprehensive plan to address larger and longer-term goals.

When I think of Olivia, I think of her as, she brings the compassion and that kind of instruction to the kids. I bring the problem solving, logic. Not that she can’t problem solve and not that she isn’t highly intelligent. She doesn't go to the level that I do of planning ahead and organizing things. We have a whole series of interactions. My
wife once expressed her frustration saying, ‘Every time I leave the house with the kids, they’re in tears’. She would be sometimes sleeping in a little bit, and I’d get the kids ready and we’re just out the door and there’s absolutely no blip, no argument, and if there is, it’s usually shut down and it’s over and we’re on our way. Olga would sometimes sob for a half hour as Olivia is trying to get her out the door to go to pre-school. Olivia had seen me doing what I was doing, but then I explained to her one day ‘I’m putting everything out and I’m making Olga choose her clothes tonight for tomorrow so there’s no argument. She has the choice now and that is not going to hold us up tomorrow.’ Now actually, Olivia does that. When I go out of town, she lays out all of their stuff. She goes through the same kind of patterns and rituals. Our kids very rarely, Owen never has an issue with anything leaving the house. [Oscar]

Cathy and her husband Chris are at a different phase compared to the other families because Candace is already in her thirties. Many of the strategies they have learned along the way have afforded them the opportunity to plan much farther into the future. Now, Cathy and Chris find themselves thinking about what it might be like for Candace long after Cathy and Chris pass on.

We're kind of at the end of our parenting. We're going to continue emotionally and financially supporting Candace, but I don't see that we're going to change strategies unless something happens. The other thing, we have long-term care insurance for Candace.
People sometimes in their 40s and 50s have strokes or are incapacitated. She's really taken care of, not just under normal circumstances but under difficult circumstances.

She accepts that we're sometimes going to get annoyed and yell at her and be exasperated, and we accepted that we're not infinitely patient. I think everybody's made peace and the plan will go on. It's good like that. I don't feel like there are any huge decisions ahead.

We've made them all. [Cathy]

In sum, having a child on the autism spectrum had a significant impact on the participants of this study. At times, the participants felt that they could not relate or that their spouse could not relate to their child. This study also illustrated the complications and advantages of having a parent with similar autistic tendencies. Unfortunately, the complexity and the frequency of these challenges often led to parents feeling overwhelmed by their child’s needs. To find balance, participants in this study used specific strategies such as devising both short and long-term plans to help them manage day-to-day tasks but also life and financial planning for their child. Lastly, parents found it extremely important to dedicate time to each other and for themselves. In doing so, they found that they managed their overall time better and felt they were a better parent and partner because of it.

**Cluster 4 – Impact on Family as a Whole**

Aspects of autism that have negatively impacted the family unit included overall disruption of family, relocating the family’s residence to be closer to services, financial hardship due to the cost of services and products, and outings such as vacations (Fong, Wilgosh, &
Sobsey, 1993; Myers, Mackintosh, & Goin-Kochel, 2009; Aylaz, Yilmaz, & Polat, 2012; Cashin, 2004). There were several instances in the literature that documented the challenges for siblings. One parent recalled, “He only goes on these outings because we make him go on them, and then he complains constantly” (Fong, Wilgosh, & Sobsey, 1993, p. 110). Although not found in my study, it was clear that the experience for siblings was perceived by them as limiting and unjust. One parent noted, “His brother is angry with us saying, ‘you are not paying attention to me, you are only interested in him’…” (Aylaz, Yilmaz, & Polat, 2012, p. 399). In contrast, and more in alignment with what I found in my study, one parent commented, “Has made us better people, taught me to appreciate the small steps and has made his sibling more open to accept all people” (Myers, Mackintosh, & Goin-Kochel, 2009, p. 674).

Although not found in my study, some families attributed their overall success to God or a spiritual being. One parent suggested, “He [God] planned something better for me, for the child, for my family” (Oprea & Stan, 2012, p. 4193). Although there was some mention of spiritual beliefs in my interviews with parents, it was along the lines of how their daughter, for instance, went to a private, faith-based University even though they did not consider themselves to be a deeply religious family. Instead of a supernatural power explaining life and autism, the participants in my study used scientific terms and concepts to explain the diagnosis process, interventions, best practices, and scientific results to show efficacy.

There were references in my data that suggested having a child who was recently diagnosed was simply too much to handle over time for the family. The volume of disruptions, behavior outbursts, and having a husband who had similar characteristics was very challenging for the rest of the family. To combat the feeling of being overwhelmed, parents found it necessary to effectively balance quality alone time with their children and their time as a family.
unit. Additionally, it was also critical for each of the families to incorporate a strengths-based mindset especially as it related to educational and social outcomes. It was common for parents to share successful approaches and strategies with their partner once they found something that worked. When possible, they bundled these strategies and approaches into a bigger “tool box” of strategies and used them to help devise a long-term plan for their child. Hoogsteen and Woodgate (2013) had similar findings in that many of their parent participants expressed the need of an action plan. Moreover, the parents in that study shared that by being open about autism with each other and with others, they were more likely to get support from those around them. Although strategies were employed by both my participants and those described in the studies, it was clear that several factors made the parental experience feel like autism was too much to handle. Parents documented the time and overall commitment that was needed to support their child in areas such as grooming, homework, managing medication, and seeking services (Ray, 2002; Gray D. E., 1993; Gray D. E., 2002; Hoogsteen & Woodgate, 2013b; Scorgie & Sobsey, 2000). DeGrace (2004) reported that parents in her study used routines and structured days as a way to manage an otherwise chaotic day. She also reported that parents tended to live moment to moment, always guessing as to what would happen next with their child (DeGrace, 2004).

Opposite of my findings, parents found that they had experienced less of everything due to the high demands of autism (Cashin, 2004). Although my participants suggested that the challenges they faced were daunting, it was clear that they felt that they had access to the tools and resources to push through the difficult moments. As a result, the words used to describe their quality of life were along the lines of “tragic but we managed” or “we did the best we could with
Challenges

*Blame and guilt.* Feelings of guilt were explicitly stated with two out of the three participants but all three families alluded to the notion that they were always afraid of how their other child would react to having to put so much attention, time, and resources into the child with autism. This sense of guilt as a parent is well documented throughout the literature. Less documented was how siblings expressed their feelings of blame and guilt towards their sibling with autism. Below, Cathy shares how blame and guilt manifested among her children.

Well, that's an awful story, but Cane committed suicide when he was 23. He was a true child prodigy. He was super-tuned in to other people, and like Candace, he never understood why people did what they did. I think Candace senses this, his suicide, I think had something to do with her, and that he felt very guilty. Everything was super-easy for him. He was very popular, he was very athletic. Like I said, he was ahead of her in school. He would try to help her with schoolwork but he was a kid and it would drive him crazy, as it did us. He felt guilty that he couldn't be patient with her. It was really difficult when she was in late elementary school, junior high, high school, being patient with her. It would take superhuman effort.

They had a difficult relationship. Candace adored him but also it was difficult for her because everything was a struggle for him.
Like I said, I think he did better than you could expect a kid to do. He was extremely sensitive and he felt responsible for everybody and everything. Life was difficult for him because of that. It was very difficult for her when he died. [Cathy]

Economics of autism. Time, energy, and money are precious commodities when it comes to raising a child with autism. Even though the participants in this study were established professionals with secured tenured positions, they still referenced the economic hardship that autism can bring to a family. In an earlier excerpt, Oscar mentioned, “…it was going to cost $2,000 and it would take at least six months before we found out…” He further explained how it can be extremely time consuming, costly, and physically draining on families to get a diagnosis, let alone seek services in and outside of school. Cathy recalled a time when her children were young, the schools her children were enrolled in were expensive, and meeting the expectations of neighborhood children was considered to be an emotional and financial hardship.

Finances were tight because if one person is a temporary adjunct they get paid nothing and the private school we had Candace in, and we sent Cane there, too, and it was quite expensive. The house we bought in Memphis was when interest rates for houses were 18 percent. [laughs] So the economy was really bad. There was a tension but I don't think the kids were too tuned into it...the other neighborhood kids would come over to our house after school and everybody wanted snacks and that was a financial burden. I was embarrassed about it. Kids' expectations are [that snacks need to be] individually wrapped…[and] it's really expensive. There was
about, besides them, maybe four other kids that were there every day. It was difficult in Memphis because they went to a private school…We were constantly trying to find activities, which meant complicated logistics. Life was a bit of a zoo in those days. [Cathy]

Comparing child to parents, siblings, and extended family members. Although Oscar and his wife Olivia are able to use humor to reflect on how they compare themselves with their children and with the other child, it was clear in the interview that in the moment as the situation was unfolding, it was extremely difficult for Oscar and Olivia to understand why their children, particularly their son with autism, behaved the way he did. Oscar provided insight into how they as a family compared with one another.

Olivia and I talk about it jokingly, a couple of different aspects with our kids. Olga is much like Olivia, very compassionate. Olga will have a lot of tantrums about something so trivial. And with Owen, I’ll say ‘Owen, I am so incredibly angry with you right now, just go away’, and he’ll just go away. Julia will burst into tears and say ‘you’re saying mean words to me’. When I think of Olivia, I think of her as, she brings the compassion and that kind of instruction to the kids. I bring the problem solving, logic. Not that she can’t problem solve and not that she isn’t highly intelligent. She doesn't go to the level that I do of planning ahead and organizing things. We have a whole series of interactions. [Oscar]

Cathy admitted that she and Chris tried not to compare their two children but it was difficult for several reasons. It was difficult because of her children’s discrepancy in physical
stature was so dramatic, Candace being older, yet so much smaller than her brother. She explained that many people expected her daughter to be younger based on her appearance and because of her less advanced social and academic skillset. Conversely, their son was very athletic, much larger in stature, and academically gifted. It proved to be very difficult, particularly as they got older and attended the same high school. Eventually the difference was apparent because Candace had been held back a grade and enrolled in mainstream classes while Cane had skipped a grade and was taking advanced placement courses. It was also difficult because conversations between Cathy and Chris often led to comparing Candace with their son Cane.

He would try to help her particularly with her math, but he would get frustrated. That was difficult for her. It's one thing to have an older sibling, because of course they're going to be ahead of you, but it was difficult. He was very athletic, and she basically still can't do simple things. [Cathy]

Although parental insight did come about as a result, Cathy also suspected that the comparisons they made also caused conflict between Cathy and her husband, placing ill-spirited blame and causing irreversible guilt. Cathy recalled a specific time in her children’s life when it was particularly challenging.

They both played chess. The private school they went to had a very, very competitive chess program and that was good for Candace because it helped with her spatial ability and, particularly in those days, not very many girls played so she wasn't very good
but she managed to win quite a few trophies because they did girls separately from boys.

I think that was good for her self-esteem but, of course, Cane, at this point, he was at one time the sixth rated kid his age in the country and was playing in national tournaments...he was going to adult tournaments and he always won money. There was a lot of press coverage too, so he got a lot of attention. She never said anything but I'm sure that's difficult for siblings.

I think having him for a brother probably complicated her life a lot, but you can't choose your family. [Cathy]

Sam and Sally shared how they struggled in the early days as they were trying to make sense of their son having being diagnosed with autism. They recalled a moment when they were reflecting on Sally’s cousin and realized that he, too, probably had a form of undiagnosed autism. Sam recalled, “I think my wife has some family members who have Asperger's. This guy likes to chase storms, but at the expense of being a very, very shy and withdrawn person. He comes here twice a year to go, or once a year in the summertime to go chase monsoons. He does it by himself. He doesn't really care about socialization skills, things of that nature.”

Sam also shared how he was always afraid that his younger son would resent the fact that he had to pay a great deal of attention to their older son, running the risk of not spending enough quality time with his younger son. Sam believed that this did not end up happening because they made it a point to spend time with each son and also as a family unit, such as enrolling in karate classes and going to the show together.
He's [Seth] the social animal. The social butterfly. He's in a fraternity. He's got a girlfriend. He does everything a 20-year-old does and maybe some things we don't hear about, I'm sure. We are always concerned that, we obviously spend a lot of time with our oldest son -- school, teaching, tutoring, et cetera, We're always concerned about the fact that our younger son would resent that, and would demand extra time of us.

But, that was never the case. He's actually been -- I think it's a reflection of being very nuclear. He is very supportive of his brother. Of course, they fight once in a while, just like brothers do, but he understands what we have to do for our older son. He also understands that the challenge that our older son has faced, he's actually faced very well, with a lot of dignity and very successfully.

He has learned to roll with the punches. He never demands extra attention. Sometimes he demands extra money. [laughs] He's always been very, very helpful. He's always willing to help his brother. [Sam]

Overall, the participants in my study experienced significant challenges related to managing their relationships with spouses, children, and extended family. It was also clear that the financial aspect of matching services, paying for schools and programs, and the diagnosis process was considered to be a financial hardship. Lastly, blame and guilt among the siblings
was always on the minds of parents and in some cases, the negative effects of these feelings actually manifested with the participants and their families.

**Strategies**

*Time with child and family unit.* Each of the parents in this study explained that it was very important for them to spend time with their children as a family but to also spend quality one-on-one time with each child. In this context, Cathy explained, “I would try to always do things with Candace separately.” Oscar expanded,

I was thinking of the timing thing with Olga or whether she might feel a little neglected. I don’t think she does because she can just go play by herself and she often will. And then Olivia gives her an inherently large amount of attention, and Owen, too, so neither one of them feel like the other one is getting more time. Because Olivia and I -- Again, we alternate who reads to who each night. I take them on long bike rides. Olivia will take them to some birthday parties so we just rotate. This past Sunday was an example where each of them had dedicated 100% time. Olivia and Owen had negotiated that he and she would go out for lunch for sushi and that he would get to go to Target to pick out his own shampoo, toothpaste and other toiletries. I don’t know where this is originating from but whatever. Olga and I decided that we would bike downtown and she and I would have brunch out then we’d go to a park and maybe one store and then we would arrive at home. I was with Olga about three hours. Olivia was with Owen
for three hours. And then we will probably invert in a couple of weeks and will switch who had who.

Sam and Sally explained that they, too, were concerned how their younger son was impacted by all the attention that they had provided to their child with autism. To find a balance for their family their solution was to spend time with each other as a family unit, often enrolling in classes and formal activities where they can be around each other. It was important for Sam and Sally to create a sense of companionship and respect for one another and to avoid competition.

The things that we've done though, we've done as a family. We trained in the school of karate, always being conscious of the fact that none of us were going to advance ahead of any other. We are what's called EQ, which is basically an exhibition short of a black belt...you know, a Shodan. I'm sure some of us could have advanced a little bit faster, but we made it a point that, if we're going to do this as a family, we're going to advance as a family.

We've always tried to include everybody in all of our functions. We still take vacations together. We go to shows together. My younger son has a girlfriend. My older son has a friend who he takes to shows once in a while. We do it pretty much as a family and we think that's been pretty successful as far as our family goes.

I credit [Sally] more than myself. She likes to make sure that when we do functions, we do them as a family. When I was in the private sector, I used to do a fair amount of traveling. She made sure that I
limited that amount because we had a child to raise and we had to
do a lot more to raise him, as far as going to school. I think she
emphasized that we spend so much time at home. She was very
stern about the fact that we sit down and we have dinner together.

[Sam]

Find strengths and positive mindset. Cathy shared how she was always very supportive of
her daughter when traveling abroad because she wanted her to experience life and allow her to
eventually become more independent. Even though there were many occasions where she
received a phone call late at night from her daughter that she had lost her passport, missed her
flight, or went to the wrong airport, Candace always found a way to overcome these challenges.
Cathy believed that her unconditional support and her focusing on Candace’s strengths played a
major role in helping her daughter experience greater success. The best example of this is when
Cathy observed her daughter excel in learning Spanish as a second language and the Mexican
and South American culture. Candace excelled in learning Spanish so much that on several
occasions she passed as a native Spanish speaker.

One of the parents wanted his money back, because they had been
promised a native speaker and Candace was not a native English
speaker, she was a native Spanish speaker. [laughs] And that really
pleased her, and so she was often able to pass for a native Spanish
speaker. This was something that I think really helped her ego, and
she has been all over Latin America, and she's traveled a lot by
herself. It's not that she's good at it, but she always gets home.

[Cathy]
As a parent, Cathy felt a sense of pride and she believed that this was a great compliment to Candace which helped her self-confidence while traveling abroad. Sam shared a similar story, which featured how proud he was of his younger son.

[Seth] is not ashamed of his brother. He doesn't feel any social pressure having a brother who has autism. As a matter of fact, he goes out of his way to use his brother as a symbol of strength. For example, he's in a fraternity now. I guess a lot of the kids in the fraternity were not doing well academically and were complaining about what they have to do. My son got up there in one of his meetings, he said, ‘You have nothing to complain about compared to my brother. My brother has a perceived IQ probably half of yours and yet he can do better than you. Why is that? Because he has the drive and he's willing to take risks.’

I was rather proud of my younger son for saying that. He actually believes that too. He believes that hard work will get you somewhere. He likes to play, too, of course, but he believes that. He's bought into the things that we have to do with our older son to get him to where he has to be. I think he uses that as the yardstick, where he actually understands now that his older brother takes it to the limit. He takes whatever resources he has and tries to make the most of it. He understands that and I think he respects that. [Sam]
“It takes a village”. It was a common theme amongst my participants to indicate that they could not have raised their child with autism alone. Even though some of them mentioned that there were times as if they were alone in their efforts they quickly reminded me that they purposefully sought support from their spouse, professionals in the field, demanded resources from the schools, and accessed public and private services in the community. In short, their success as a parent raising a child with autism had much to do with them welcoming and seeking support from others. Sam said it best, “It is one of my concerns where other kids with high-functioning autism will have this dream and aspiration of going to college could certainly happen. It could certainly happen, but there's got to be a lot of players involved. What is that common saying? ‘It takes a village.’ It really does. It takes a lot of support. Fortunately, we were able to provide it so far.” [Sam]

In sum, the challenges that each family experienced were unique to their own life experiences but there were several themes that ran through each of the stories. By spending time with their children they found the opportunity to appreciate the uniqueness of each child. In doing so, the other child was less likely to feel neglected or left out. Each of the families treated their child with autism as a member of the greater family and included them in all of the activities that the family would normally have participated. This sense of inclusion was a common theme throughout all three participants’ interviews. As time passed, particularly as school become increasingly academically rigorous for the child, and as more demands were put on the parent, it became even more important for the parents to find positive aspects of their child to help them build off of those skills and to help filling their skill gaps. Focusing on their child’s strengths encouraged their child to build greater confidence in themselves and to experience greater success in their educational and social environments.
Cluster 5 – Full Integration into Society

Overall, the primary objective for all three of my participants was to have their child be fully integrated into the greater society. Along the way, parents worried about the future, lacked support from friends and family, were subject to social judgment, and felt embarrassed at specific moments during their child’s development (Aylaz, Yilmaz, & Polat, 2012; Cashin, 2004; Fleischmann, 2004; Oprea & Stan, 2012). Another theme that ran throughout my study was that by the time each of the families had accepted their child for who they were as an individual and how they had developed as a parent, the participants were content with things and had no desire to change their family circumstances. They were not interested in finding a “cure” for their child’s autism. Instead, they loved them for who they were even during the most challenging times. In Myers’ and associates’ (2009) study, one of their themes was titled, “Glad for child’s autism, uniqueness would not change” (p. 677). Fleischmann (2004) used the following quote to demonstrate how parents did not want to change their son, “Would I change him? No, not for the world” (p. 42).

Congruent with my data, the literature suggested that the parents of children with autism felt that our society as a whole lacked understanding and empathy (Hoogsteen & Woodgate, 2013a; Scorgie & Sobsey, 2000; Ray, 2002; Aylaz, Yilmaz, & Polat, 2012). Judgment is often placed on the parents, especially mothers, who cannot seem to control their children in public spaces. Stereotypes are assigned to the children and parents often found themselves receiving advice from friends and community members who do not know what it is like to raise a child with autism. Parents in my study reported that they eventually learned how to manage these expectations and unfair judgments by turning their newly acquired knowledge into a commodity. They recognized a need to help other families who were going through similar challenges. In
turn, they taught others how to be self-advocates and to be an advocate for their child. Through this informal process of outreach and education to others, their own sense of self-worth and confidence increased. Ray (2001) first referred to this process as making the invisible, visible. Essentially, as parents learned more information and specific strategies that were effective for their child, they gained greater insight into the world of autism. As a result, the parents with children with disabilities placed value in helping others because they understood what it was like to have the feeling of sinking, floundering, or hopelessness (Hoogsteen & Woodgate, 2013a). Scorgie and Sobsey (2000) wrote that parents felt enriched and rewarded by educating others because they facilitated positive social interactions with families and within the greater community.

Gray (1993, 2002) documented that keeping autism invisible to the rest of the family and the community led to stress and isolation. Conversely, by sharing insights with spouses, educating others, and talking openly to specialists, it provided a vehicle for the parent to share their knowledge and be perceived as an expert in their child’s case, which led to greater perceptions of confidence and self-worth (Gray, 1993). Unlike my participants, parents in the Woodgate et al (2002) and Gray (2002) studies used “isolation” to describe their specific interactions with health and educational institutional systems. For instance, one parent wanted a good introductory book on autism for parents but had difficulty finding one. Parents felt that if their child’s physician or other specialists would have a short list of related resources it would help them connect with other experiences (Woodgate, Ateah, & Secco, 2008). For their overall experience, families used the word “inclusion” but only as a result of constant “pushing through” and exhibiting a strong sense of “drive” did they actually achieve it, which was similar to my findings.
Woodgate et al (2008) expanded on the concept of isolation in an article that described parents feeling as if they were living in a world of their own. They found that parents perceived to be on their own in all aspects of autism, particularly as it related to the differences and challenges when parenting a child with autism (Woodgate, Ateah, & Secco, 2008). A related study supported these findings suggesting that parents of children with intellectual disabilities felt on their own and isolated (Mackey & Goddard, 2006). Although the parents in my study did not overtly suggest that they felt on their own or isolated for their overall experience with autism, it was common for them to provide examples that implied there were times throughout the process of raising their child that they felt alone and by themselves. When it got to be too much emotionally or physically, they said they were fortunate enough to have the support of their spouse to share the responsibilities. They stated that by dividing the labor between the both of them it allowed them to get things done for their child and family.

Although it was not documented as extensively in the literature, my participants had strong opinions, hopes, and fears when it came to the future of their children. They reflected on questions such as, *What will they do when I’m not around?* or *Will they be able to have healthy and successful relationships? Will they find a romantic partner who they will be able to share their life?* Fong and associates (1993) found that parents were concerned about how their son or daughter would handle themselves during sexual or romantic situations with peers. One parent expressed concern about the lack of information to help educate her child, “There isn’t enough information on what to expect or how to handle it” (Fong, Wilgosh, & Sobsey, 1993, p. 111).

After interviewing my participants, it became clear that each of them made a concerted effort to provide their children with as many authentic experiences as possible in hopes that they would be more prepared for mainstream living. When enrolling them in schools, they advocated
on their behalf to be in mainstream classrooms. In career preparation, they supported their child when pursuing a driver’s license. And when in college, they helped them seek the appropriate accommodations and support services. I found that the future was an important topic for my participants.

Although I did not find a study that documented what it was like to have a spouse with either autism-like characteristics or a formal diagnosis, I found this phenomenon to exist in my study. I suspect that the lack of studies on this topic had more to do with where we are on the phenomenological timeline of autism than it had to do with anything else. I found in my research that those fathers who had self-identified as having autism were between 40 and 60 years of age, which would mean that when they were children, or even young adults, much less would have been known about autism, particularly Asperger’s syndrome, thus severely limiting the population sample and the awareness of resources available to them at the time. Nonetheless, having a spouse or partner with autism-like characteristics made raising their child a more challenging situation.

Challenges

*Society’s limitations.* A common theme among all three participants is that society as a whole has very little patience and understanding for those exhibiting autistic characteristics. Participants felt there were gaps between our society’s knowledge of autism and the realities of early identification, the diagnosis process, services and products, and interventions. From these families’ perspectives, it is clear that even those close to them, such as students enrolled in their courses, family and friends, and colleagues in their professional networks, simply did not have a good understanding of what it takes to support children and even adults who have autism.
When I look at where we are, on the whole...Not just autism, but differences in learning abilities, I don't think that there are really great mechanisms yet for identifying when someone who is naturally brilliant and who has a learning disability. It might show up very, very late. I don't know what the literature says about this, but I've observed it with students far too consistently, where a brilliant student has masked whatever it is, and then they are pushed to their utmost limit and they start failing for the first time. They don't understand why, and they flail around and they try different techniques. If they could be found earlier and trained earlier in the skills that will help them when they do reach that point, 15 years later, that would be ideal. [Oscar]

Oscar points out that even though a great deal of progress has been made over the years, families and educators need to be more informed. Greater levels of “tolerance” and understanding need to grow regarding autism in general.

I think the social awareness of differences in people's behavior is becoming more tolerant. I follow a news aggregator website called Fark and there's a story on there about responses people had in a restaurant to someone who had autism. The response comments from the readers who read the story were much more on the tolerant side than, ‘This child should never be allowed anywhere in public.’ I think the tolerance is getting a little more there. [Oscar]
Cathy pointed out that, especially for those close to her, there was a lack of general understanding. She realized that there is a severe gap between the reality of autism and her friends’ awareness. She realized this based on the types of suggestions and advice they have offered her over the years. They assumed they knew what it was like to have a daughter who not only had a learning disability but who also struggled with social and romantic relationships.

One thing we haven't talked about, which is something that I think all mothers struggle with, is that other people want to give you advice on parenting and very few people can really appreciate the special case. And all kids are, I mean, Cane was also a special case. People were always giving me advice that made me mad. I think that's always kind of a special case for parents of kids on the spectrum, is people say, they'll say about Candace, ‘Oh, you coddle her. You help her financially. If she just had to be independent she could,’ and they have no idea. [Cathy]

Sally and Sam expressed concerns over the use of the word “retarded”. They were concerned that people felt that children diagnosed with autism cannot achieve nor do they have the potential to do great things in life. They went on to say that one of their greatest pet peeves, and perhaps one of the worst things about our society, is how we tend to place low expectations upon certain groups of children.

**Sally:** I guess that's one thing, too, because I think even when Stephen was young, and because he would be so behind on things, I think we had to break that stereotype, that he wasn't...I hate to use
the word, retarded. It's not that's it’s such a terrible term. But, a lot of people thought autistic kids are not very bright. I think just breaking down that barrier. I mean, I stood around work one time, I was saying that for high school, we're going to try to find something for Stephen that would challenge him a little bit. I remember, I had another pharmacist say, ‘Why are you doing that for?’ I'm looking at her like, ‘What?’ I was just, ‘You don't know.’ Anyway. But it is, it's that stereotype, unfortunately.

**Sam:** I think, if I can express one of my own criticisms, I think that's one of the big limitations right now in, frankly, in society. There's been so many times where our son has been evaluated, and the first thing we ever hear is...and I have this so ingrained in my mind...that ‘your son could be a gardener's helper’, or ‘he could do menial construction work’. Menial construction work, you know? Very basic things. Then we tell them, well, he almost has his bachelor's degree in college. Then it's like, wow. People can't understand that. It makes me realize that there are still existing barriers in society today where there's a stereotype. OK? You're autistic. You can be a gardener's helper. OK? Those misconceptions are things that, unfortunately, a child with autism, one who's actually in good standing and has a B+ average at the University, is still going to have to deal with. It's rather unfortunate. [Sam & Sally]
Future fears. Perhaps the harshest reality of having a child with autism is the fact that the future is sometimes a dark place to explore because of what the families are currently going through.

Another goal I used to have, which I've given up on, her house is always just a complete disaster. It's really a cute, little house. We spent quite a bit of effort decorating it cute. I would help her get everything arranged. When I'd come over it would smell bad, and there'd just be stuff everywhere. I would say, and this was when she was trying harder to date, ‘If a man comes over and he sees your house like this, it's going to be a major turnoff. Men want people who can take care of themselves. You don't have to be a great cook, but you need to look like you can take care of yourself.’ We never got anywhere with that. [Cathy]

When Sally looks into the future she, too, hopes that her son is able to find that special someone who will care for and respect him as an individual.

Wow, well I hope for Stephen that he can find somebody that maybe he can have a relationship. I mean he has a friend but I don't think it's going to go much beyond that. She's a sweetheart. We talked about her before. I know it's going to be somebody that has to be able to understand Stephen for the way he is. Stephen will never hurt anyone. Stephen will always do what you...I don't want him to be in a relationship where he's abused or neglected. [Sally]
It became very clear to me that much of the future hopes and aspirations of the parents revolved around being able to have healthy and loving relationships. Cathy pointed out that she experienced differences based on her gender, particularly as they relate to being a wife of a man with Asperger-like characteristics. She uses this insight to contextualize her fears for her daughter.

There was an article in the *Wall Street Journal* sometime this week about gender differences. Apparently, the latest big conference in autism is looking at gender differences. I've always thought that, somehow, there may be little gender differences. There's also this phenomenon where if you're a man, you can get a woman to take care of life for you. If you're a woman, you don't find a lot of men who are going to take care of life for you so there's a difference in acceptability of these behaviors. [laughs]

There are lots of people like Chris [her husband]. Philosophy's full of them. If you go to a philosophy party, you've never seen so many socially inept people, oblivious to [social] cues. They've all got wives elbowing them trying to get them to stop whatever [laughs] they're doing. They all manage to find patient women, I'm not so patient, but patient women who will compensate for them.

It's accepted. But also, the men that I know, which is limited, who are on the spectrum are high-status males. So you'll put up with a lot from someone that you perceive to be high-status. If you were a male that was more like Candace, you probably are a lot less likely
to find somebody to put up with you. This is one of the things that always amazed me with our son. He was very much a tortured, artistic type. Couldn't keep the girls away from him. He always had girls hanging on him. They just loved this tortured...And I thought, "What a pain in the butt, he's such a downer." And all this angst -- why would you...But he was high-status because he was really smart and he was artistic. He was a musician and he wrote poetry, and he had deep thoughts. He was high-status, so there were lots of girls wanting to take care of him and put up with him. That's one of the sad...

I imagine [if] you're a [female with autism and you are a] movie star, rock star, then there's money involved. But still, those people tend to go through lots of husbands. I think, in general, society values and rewards women who take care of their high-status husbands and I don't think there's the same social utility for males.

This is interesting, it's kind of a running joke. I always tell my husband that in case I drop dead, or get hit by a truck, we have to have somebody in mind to take care of him after I'm dead. There's always this discussion who would be the appropriate person. I've thought about this. Probably some salt of the earth person, who doesn't have a career to compete with him. A lot of academic couples as you know, the competition. I think it's because my parents weren't educated. I went to top schools and everything, but
I don't have a sense of entitlement about it, because it just sort of happened the way it happened. It's not like I saw myself as a scholar. I was, but it wasn't part of any plan or expectation.

**Strategies**

*Enhancing understanding.* The lack of societal understanding seemed to really frustrate the participants in this study. However, instead of letting this reality get the best of them they turned their frustration into opportunity. It became more apparent that the primary skill they learned over time was a sense of self-advocacy. By advocating for their children, they were practicing self-advocacy skills as a parent while at the same time teaching their child how to advocate for themselves. By taking control of the situation, they relied less on others, particularly waiting for professionals to provide answers to their questions, and more on their own ability to research specific practitioners and services that could help them understand their child’s needs. As a result of their hard work and diligence, they were empowered and wanted to share that sense of confidence with others.

This confidence often manifested in having strong opinions about what worked and what did not work for their child. It also gave them the confidence to confront their friends, family, professionals about the realities of autism, particularly as it impacted their child’s education and health. In some cases they had to let individuals know that their advice was not needed, inaccurate, or simply inappropriate. Cathy explained, “It depends on how good a friend it is. I usually just say, ‘Thanks, but I don't need advice.’ [laughs] It's interesting how many people feel free to judge other people's parenting.”

Confidence was acquired over many years of experience but at some point each of the families expressed a sense of giving back to the community. They wanted to share their
experiences and in one case the family went so far as to create a formal summer program for youth diagnosed with autism. Sam’s and Sally’s goal was to create a program for adolescents to gain college skills and to help demystify the notion that they were limited to menial jobs. They wanted other families and students to know that their child could be successful in academic environments, namely college and professional programs. Sam and Sally explained it best when they shared their motivation to helping others navigate the realities of autism.

We're hoping, with the camps, that maybe it might be an introduction. There's no way we're going to be able to help all kids.

I don't know if you've ever heard this story. Kind of a cute story, but it's true. About this guy who walks along the beach, he sees this other guy. There's a whole mess of starfish up on the beach, and it's washed ashore. He sees this guy flipping these starfish back in the beach… He goes up to this guy. He says, ‘What are you doing?’

He says, ‘I'm just putting it back in the water.’ He says, ‘Why are you doing that for? There's thousands of them. He says, ‘You're only going to be able to save a few.’ And he says, ‘Yeah, but at least it's a few that I am saving.’

I guess that story always impacted me because [I can relate] to it, but that story always impacted me because I figured even like the summer camp, or whatever, as parents if we can help a few kids like this, I think that's why we're trying to do this trying to get involved with [the community]. You know, if we can help a few
kids get to the point like Stephen, I think that's one of the things we would like to share with everyone. I know. Again, that's a little side thing, but you know, I know there's a lot of people that's out there, they have their questions. What do we do now?

You know we had a couple from, the wife worked at [a local defense company], and she has a five-year-old. I think he's got some other medical problems too. She's saying, ‘What do I do? What do I do?’ She's trying to get [the company] to help.

She's been emailing Sam. We feel bad for her because we know what we had to go through, so we said, ‘keep in contact.’

‘There's some little things that you need to do,’ I said. Just try to provide the resource. I know we're not all knowing, OK? We just tell them, ‘Look, this is our experience with Stephen.’ I said, ‘This is what we've done. It may or may not work for your kid.’

That's one thing we're hoping that eventually, that once we get Stephen past the time. See if maybe we can help a few other kids like that too. [Sally]

Being Optimistic. As much as fear was a reality for the families, there was just as much hope and optimism. The parents managed their fear by confronting it head on. Their approach, across all three cases was to provide their child with authentic and appropriate support structures as they experienced real-life tasks and opportunities. The parents believed it was their
responsibility to expose their children to numerous, frequent, and ongoing “real-life” situations that challenged the child but also provided him/her with support, structure, and a sense of caring.

Oscar had a strong sense of how Owen would turn out as a result of the guidance and support he and Olivia had provided.

Yeah, Olivia and I talked about it when she was pregnant with Owen. Again, we went into this eyes wide open. OK. I can say with 98 percent certainty that Owen is probably going to go into science or engineering and he's going to go to college. It's pretty clear. It's not what I want for him, but I think that's what he will naturally select. Not because necessarily he wants to be like me, but just because his brain is so logical. He's always been that way.

His path, I envision...He'll struggle somewhat socially, and Olivia will try to help him. He's probably not going to care too much. He probably will choose activities that he seems to really enjoy, but he'll probably end up choosing ones that were similar to the ones I did, just because he does want to be like me in some ways.

He'll probably always do consistently well in school. I don't know if he'll do outstandingly well. But Olivia and I discussed when she was pregnant that we hoped he would make enough money to do whatever it was that he would really like to do and live the kind of lifestyle he wanted. That's really the big hope, [maybe] a garbage man...Actually a recycling truck driver [because he is fascinated with recycling]. [Oscar]
It became more apparent to Cathy and Chris that Candace was getting older and she would need to have better skills to life and work independently. To illustrate their proactive approach and authentic scaffolding, Cathy talked about how they purchased two investment properties and had been teaching her how to manage the properties for the past several years in hopes that she would be able to use these as sources of income.

She's more independent. The first year we were here, we bought a duplex, it's just over there [Cathy pointed south]. She lives in one side. And then we bought another duplex right across the alley. The idea is that she will kind of manage those, which will give her some income, combined with the $8,000 she earned, she kind of has the illusion of independence. Of course, she's not really. Every time anything slightly goes wrong, we have to rush over and unclog the toilet, or whatever. She is getting more independent. She has a dog, and she collects the rent, and when we need repair people she waits to let them in. She pays some bills. So, she's learning how to manage the two duplexes. [Cathy]

Almost immediately after the diagnosis phase, Sam and Sally had committed themselves to pursuing one goal and one goal only – to mainstream their son in to school and society.

Yeah. Not many. We never interacted with the Autism Society, we never...other than for Stephen to get a scholarship once. Our focus was always to mainstream him. OK? To keep him, as close as we could, attached to his age-matched peers, with his colleagues in college. We could have gone to support groups, and him go there,
but we thought, why? That's not the objective, to put autistic kids together.

I think we thought that the objective was not to, using a popular term now, sequester our son with those who have developmental disabilities. I think the objective is to get them into the mainstream. Including, even here at the university, being in class with his age-matched peers. Interacting at a university level, because that's what they're going to have to do in their careers. I doubt if any private company is going to say, ‘Oh well, you had an IEP. We'll give you two and a half times more [time] to do this project.’ They're not going to do that. They're going to expect you to be as competitive as others. I think that the goal should always be to try and put them in that mainstream with his peers, so that he can interact, and he can try to, for lack of a better word, compete.

That's why we really didn't have him interact with other kids with disabilities. We never had too many opportunities, too. We were so focused on his development that we never really even thought about that. [Sam]

In sum, the parents’ story provided a great deal of insight into what it was like to have a child diagnosed with autism. It was clear that the dualities of autism were present in my study. As parents had very daunting and at times situations that seemed to be unsurmountable, parents founds ways to cope and in many cases found a great sense of satisfaction after working through
it with their child and spouse. In many ways, each challenge that they were confronted against, it
gave them another opportunity as a family unit to conquer and become even stronger.

To get to a point of satisfaction and pride, parents and children had to demonstrate drive
and resilience. For each challenge, parents found solutions which helped them manage the
current situation but also future experiences. Although each participant had children representing
different ages (Candace: 30 years old, Stephen: 23 years old, Owen: 7 years old), there were
several commonalities, many of which I have listed above. The two overarching themes that
came out as a result of my analysis were that (1) parents had already reached a level of
acceptance of who their child was and who they’ll likely be later in life and (2) the main goal
parents had for their child was to have them fit in and be accepted into society. The idea of
inclusion was a motif that ran through the literature and my study. The following chapter will
conclude by outlining several implications that arose as a result of this study. Most significantly,
a list of recommendations are provided to help parents new to autism understand what it took for
these three families to find strategies to their challenges.
V – CONCLUSION AND IMPLICATIONS

The participants of this study describe their struggles of autism as many points in their lives that were and will continue to be extremely challenging moments for themselves, their spouse, and children. Parents who participated in my study perceived their child as someone who was different from themselves or their other parent, family members, peers, and most other members of society. Even though my participants had experienced very awkward, sometimes embarrassing, and frequently frustrating situations over a span of many years, each was eager to share their story with me. I suspect that this interaction between us was therapeutic for some. There were occasions where they said, “thank you”, referring to the opportunity to share their story. I greatly appreciated their genuineness as it allowed me to narrate their story in a context that made sense to them and that was perceived by them as an authentic use of their story. Perhaps most importantly, they granted me the opportunity to share their lived experiences because they felt the obligation to share what they had learned with other parents who would be willing and able to learn from their struggles.

In Sally’s final interview, she reinforced an age-old saying about taking a village to raise a child. She felt strong about how true it is, particularly for families with autism, to rally together to support a child throughout their life. She claimed that it would have been much more difficult if it were not for her caring and committed husband. Moreover, she reified the notion of persistence as the ultimate strategy, particularly when individuals and systems are not very knowledgeable and too inefficient. That said, she said she was very fortunate to have had access to the many resources in her community. These individuals and agencies have been instrumental to Stephen’s success and the young adult he is today.
After having had the opportunity to listen to each of the families share their trials and tribulations, it was clear that the realities are extremely challenging. As much as each family articulated the significant setbacks they faced with having a child with autism, each of them found ways to persevere and identify strategies to help them “push through”. It is this push through motif that runs through each of the excerpts identified within the interviews. Some families referred to it as a sense of “drive” or overcoming obstacles. It became clear, particularly as I began comparing the various excerpts, that the motivation behind such determination and perseverance was a strong desire for their child to have a bright future. These long-term outcomes of independence and autonomy were the ultimate goal for each of these families. Although it was difficult, and seemed impossible at the time to spend too much time dreaming for the day of total independence, it was still a major driving force for their constant pursuit of finding ways to support their child, even long into adulthood.

Optimism for the future is a critical component to experiencing successful outcomes as a parent with a child with autism. These families encouraged their children to pursue their natural interests, providing them opportunities to develop independence and ways to gain access into mainstream society. Although optimism for the future is eloquently stated by these families it is not the only strategy they used to experience success. There are many other factors involved but the insight these families have provided is that with a positive attitude, persistent approach, and a commitment to longer-term goals, many, if not all, of the realities of autism can be addressed.

Managing the realities of autism for these families has been a long and arduous process that has forced them to question their philosophy on parenting, doubt themselves as parents, rearrange their professional careers, and even adjust their social calendars to make sure that their child and family had what was needed to be successful. As a result of addressing each struggle
with time-tested strategies for their child, these families have enjoyed the fruits of their labor and have observed desirable outcomes. Moreover, parents felt that they became more empathetic towards their children and others who have similar challenges. Overall, they felt that because of their commitment to their child’s success, they have educated a fair number of individuals and professionals in the field and in the community, contributing a greater body of knowledge and understanding for everyone. In short, these parents are proud of what they have accomplished thus far and would do it all over again in a heartbeat if given the choice.

Implications and Recommendations for Families and Practitioners

There were several significant findings from this study. The most significant is that in response to each challenge; parents identified numerous strategies that allowed them to cope through very difficult moments during important parts of their child’s life. It was clear that parents wanted to share their story with me. They explained to me that there were three reasons for their willingness. The first was because they trusted me. The second was because they wanted to let other families who had gone through similar experiences have something and someone to relate with. The third, and most important to them, was to provide insight for families who were barely beginning their journey with their child and family. In essence, my study gave them a platform to connect with families on a grander scale, increasing the likelihood that they would be able to help other parents make good decisions for their child and family.

Below is a cumulative set of statements that originated from the participants’ stories and were reviewed and approved by the parents themselves. My goal for this study was to represent their story in a way that accurately represented their struggles but also featured how they pushed through to make their situation better for themselves, child, family, and their community. In consultation with the participants, I formed statements that represented how they wanted to
provide advice to others based on what they had learned during the trial and error process. As parents, they wished to help me create this list so that other parents would not have to struggle in the same ways as they did or as much.

1. **Time is of the essence**: The sooner you accept something is different, the sooner you can begin your journey. Do not ignore the oddities, weird behaviors, and shift in language development, because the longer you delay, the less opportunity there might be for an early intervention. Seeking diagnosis can be an emotional and psychological rollercoaster, but use diagnosis to be a starting point to initiate awareness, education, and overall acceptance of autism.

2. **Don’t play the blame game**: When pursuing the formal diagnosis process it is important to abstain from placing blame, on yourself or others. The tendency might be to try to identify family members who may have genetically “passed” on the autism gene. Since science has not been able to identify such a gene there is very little good that comes out of trying to figure out where autism came from. This can be especially challenging if you begin to blame yourself or your partner. Instead, it is recommended that you become educated on effective ways to cope with the realities of autism and to engage in healthy dialogue with your family and friends. Attempt to find a balance between taking ownership and carrying too much of the heavy burden of blame.

3. **Push through, no matter the struggles**: As a result of bureaucratic and ineffective health care and education systems it is important for you to sustain a fight attitude. Although you may encounter ‘red tape’, keep on pushing through the barriers in order to get adequate services for your child. When trying your own strategies, feel free to use trial and error when it comes to finding what works for your child. There is still limited
knowledge when it comes to the science and technology related to best practices, interventions and etiology. Although a pushing through attitude will be tiresome and perceived as more work, you are likely to experience greater short and long-term success.

4. **Self-time does not mean selfish:** If you feel disconnected to your son or daughter find ways to gain perspective from your child’s vantage point. By understanding what your child is thinking and feeling, you will gain greater understanding into what may work for them. Let your child know that you will always be available to them, no matter how busy you may be. Let your partner know that their ideas and suggestions matter as well. It is recommended that you take time for yourself. By doing so, you will allow yourself to reflect on what worked and to plan accordingly for the future. This self-time may also be an effective approach to release stress, refocus and refill the reserves. Self-time means something different for each parent.

5. **Plan, plan, and plan some more!** Take the time to project out to the future and while doing so, ask this question of yourself, your partner and if age appropriate, your child with autism, “what do I want for my child?” By doing so, you will begin the necessary planning process to reach desirable outcomes. Use mini plans to guide daily routines, grooming and other pattern-like behaviors. It is also recommended to bundle several mini plans to create larger goals and steps to achieve those goals to support longer-term goals such as greater independence and confidence. Once a mini plan is in place, practice changing the plan slightly to teach yourself, your child, and family that plans and goals are meant to be adjusted and changed.

6. **Embrace your resources; teach your community:** Although friends, community members and the greater society can reinforce the harsh realities, it is important to remember that
your community could be your greatest asset. Over time, feel free to share your experiences with other families who may be in early phases in the process. Identify safe and welcoming groups and agencies that would welcome your insights and begin to share your story. Initially, this may feel awkward and embarrassing; there may be much to gain from this process for you and your audience. When sharing your story, share how your (high) expectations helped shape who your child is and who you want them to become.

7. *Think positive now and for the future:* One of your greatest challenges may be maintaining a positive attitude when thinking about the future because your day-to-day activities may be extremely overwhelming. To contrast this feeling, do everything in your power to provide your child with as many rich and authentic life and work experiences as early and frequent as possible. By doing so, over a long period of time, your child will be exposed to incremental and developmental appropriate introductions to mainstream society. It is also encouraged for you to learn about your child’s natural interests and to identify programs and services that will help them develop these interests and passions.

**Conclusion**

Our overall knowledge of autism is extensive and far from when it was first thought of more than 100 years ago. That said, there is still so much more to learn particularly as autism intersects and overlaps in the fields of science, education, sociology and the many other disciplines. Our knowledge in genetic linkages will continue to enhance as we discover new aspects of the human body, brain, and its systems. Our criteria needed for diagnosis will continue to evolve as well as the reliability and validity of tests. Our understandings of the various types of interventions will become much more sophisticated as time goes on, particularly as we develop new technologies and medicines. With these great advances it will also be very
important for us, as a greater society, to continue to integrate the lived experiences of those who are experiencing the realities of autism first-hand so that the science and protocols are complimented with the real-life experiences of the child, parents, and families. By advocating for an integrative approach for autism, we are likely to recognize that there are many benefits to having greater understanding of one’s perspective. Perhaps, it would allow us to entertain the notion that those with, what we now call autism, simply have a set of characteristics of natural human behavior on a very complex neurological spectrum that defines the human race. In other words, the realities of autism are essentially the realities of humankind. It is my opinion that by accepting this stance, we are likely to embrace the diversity within human nature and broaden it even further.

It is clear that the families with children diagnosed with autism have a very difficult time dealing with the complex nature of autism and all of its moving parts. But it is also clear, at least for those who participated in this study, and those who participated in related studies found in the literature, that parents are willing to accept the challenge, take ownership of their role and infuse strategies into their daily practice so that their child can experience greater levels of support in educational settings, life, and beyond. Their pushing through attitude and their resolve are a testament to future success for themselves as parents and for their children. Lastly, what is most impressive about those who participated in this study was their overall commitment to outreach and education to and for others in their respective communities. It was clear that they gained a great sense of pride in helping others learn from their personal experiences with the hope that by helping, if only a few, that it would not only be worth it, but the gesture would grow exponentially as others engage in the same process. The joy and pride seeing their own child
experience success was fulfilling, but the accomplishment they felt when other children experienced it was ten-fold.

It became clear to me that my study provided a unique perspective because two out of three participant families had fathers who exhibited Asperger’s syndrome characteristics and the third had an uncle with similar characteristics, yet they were all undiagnosed. Although this phenomenon was not a central point in my study, it is an area that provides yet another layer of complexity when understanding the lived experience of the parents, particularly the neurotypical spouse. When reviewing the literature, there were very few studies that systematically addressed this phenomenon, and I was unable to find any studies that provided insight into this from an insider’s perspective, suggesting that this area is ripe for further study.

It may also be worth mentioning that my study may have also exposed a potential population that might have greater prevalence for autism, particularly those considered to exhibit Asperger-like characteristics – the University campus. Due to convenience sampling, all of the participants had faculty or researcher roles. It is known that commitment to any discipline at the highest levels requires a type of focus that is unlike almost any other. It requires attention to detail, sustained over long periods of time - often in units of years and even decades. This type of activity and extreme focus lends itself to Asperger-like characteristics, perhaps resulting in greater numbers of individuals who have, over time, filled these roles in our society. Future inquiry on this topic is of particular interest and might lead to interesting findings.

In sum, the results of my study were in alignment with much of the literature, yet provided new insights into areas that have not yet been fully explored. The participants of my study provided a unique perspective into the realities of autism and were gracious enough to share some of the strategies they used to experience success. Although it was extremely
challenging for them to maneuver through the complexities of autism with their child, they provided great examples as to how a parent could cope with autism and in the end, be that much of a better parent and person because of it. This story is as much about shedding light into autism as it is about sharing heart-felt stories that provide inspiration, hope and a plan for future families.
APPENDIX A: Interview Protocol

Interview One: Focused on Life History
*Ask participant about how s/he came to her/his work.*

Goal: Find out as much as possible about the context of her/his life leading up to her/his present.

4. Tell me about your son/daughter.
5. Tell me about your life up until now, specifically about how it relates to your role as a parent with a child who has autism and go back as far as possible within our time frame of 90 minutes.
6. Tell me as much as possible about yourself related to your role as a wife/husband, partner, parent, community member and how it relates to having a child with autism.
   a. For professional/educator: professional, career, educator, researcher, advisor, teacher.

Reconstruct early life experiences with regards to your family, school, friends in your town/neighborhood and work.

Share with me about your friendships, relationships, educational experiences, work experiences, undergraduate and/or graduate work, early teaching experiences of which led to who you are today.

Put your parenting, career decisions, and relationships in context of your life history.

Interview Two: The Details of the Experience
*Ask participant to tell as much as possible about the details of her/his experience as a parent with a child with autism.*

Goal: Focus on concrete details of their lived experiences in the area of study

1. What is your work? What roles do you play in the family?
2. What is it like for you to do what you do?
3. How do you think you do it similarly/differently to others?
4. Describe your relationship with your children, partner, family, neighborhood, wider community or
   a. For educators: students, mentors, faculty, administrators, staff, parents of students, and wider community.

Reconstruct a day in your role from when you wake up to the time you fall asleep.
Share a story about an experiences that illustrates your experiences as a parent with a child with autism.
Interview Three: Reflection on the Meaning

Ask participant what her/his parenting/work means to her/him.

Goal: Reflect on meaning by placing emphasis on intellectual and emotional connection between participants work and life.

1. Given what you have said about your life before you became a spouse/partner, parent, professional/educator/researcher and given what you have said about your life and work now, how do you understand your role as a parent in your life? What sense does it make to you?

2. Future: Given what you have reconstructed in these interviews, where do you see yourself going in the future?
   a. What do you hope for your children for the future?

Now that you have talked about how you came to your role as a parent/work and what it is like for you to do that work, what does it mean to you?

As you’ve identified some of the factors that have shaped who you have become as a parent, how have these factors helped shape who you are today?
APPENDIX B: Disclosure Letter

Disclosure Letter

Project Title: Lived Experiences of Families of Children with Autism Spectrum Conditions

You are being invited to take part in a research study and asked to read this disclosure letter so that you know about this research study. The information in this form is provided to help you decide whether or not to take part. If you decide to take part in the study, your active participation will suffice. If you decide you do not want to participate, at any point in the study, there will be no penalty to you, and you will not lose any benefit you normally would have. This study is not designed to be generalizable and the scale of which is small enough to not require IRB approval.

Purpose:

The purpose of this study will be to explore, using qualitative methods and storytelling analysis techniques, the lived experiences of family members, particularly parents of children with autism spectrum conditions (ASC).

Participation:

You are being invited to participate in this study because you are a parent or family member who has a child who has been diagnosed with autism or you believe s/he has autistic characteristics. Three to five participants will be asked to participate in the study.

Details of Study:

This study involves qualitative methods such as in-depth interviews and may include, depending on the participants availability and willingness, observations, artifact collection and field notes. The researcher will use participant observation techniques to gain insight on the community, family and social setting in which participants engage. Such techniques may include intensive and systematic observations of the activities in their natural setting. Both indirect and direct forms of observation will be employed yielding insight into behaviors and reactions to occurrences in their natural settings. Interviews will be one-on-one, open-ended and for the most part unstructured, allowing for the participant to expand on their memories, perceptions and experiences. Interviews will be recorded using a digital device. Transcriptions of the interviews can made available to the participant upon request. Open-ended questions also allow for both the participant and researcher to follow-up on specific questions either in the interview session itself or observed in a prior setting. Lastly, the researcher will be using field notes and artifact collection to compliment data sources for analysis and interpretation. The researcher will record his field notes after the observation opportunities to allow for the capture of real-time lived experiences as they are happening, respecting the natural life experiences of the participant. The types of artifacts the researcher may collect will vary. For instance, email correspondence, sample writings, journal entry excerpts, poems, writing samples, reports written about the participants, medical and various educational documents.
The researcher does not seek to generalize these stories. Instead, the goal is to illustrate using stories, or portraits, the various and diverse ways parents of children with autism view, experience and change the world.

**Data and Confidentiality:**

Information gathered for this project is confidential. Your name and identifying information will be collected to link your responses back to your name. Once all matching data is obtained, the personal identifiers will be removed and only a pseudo name will be used to identify each data record. Any data used in published reports, presentations, and publications will contain no individually identifying information.

**Risks:**

There are no known risks if you participate in this study. Although we have tried to avoid risks, you may feel uncomfortable disclosing certain information about yourself. If this occurs, you can stop participating immediately or ask to move on the next question.

**Costs/Benefits:**

There are no costs (aside from your time) and no direct benefits to you as a participant in this study. You will not be paid to participate.

**Additional Information:**

You can call the Principal Investigator to tell him about a concern or complaint regarding this research study. The Principal Investigator, Rudy M. Molina, Jr., M.A. can be phoned at (520) 822-7044. Although this study is not required to be on file at the UA IRB office, if you have questions about your rights as a research subject you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. If you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator; or want to talk to someone other than one the Investigator, you may call the University of Arizona Human Subjects Protection Program office. If you would like to contact the Human Subjects Protection Program via the web (this can be anonymous), please visit [http://orcr.vpr.arizona.edu/irb/contact](http://orcr.vpr.arizona.edu/irb/contact).
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