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**WHAT WE CAN LEARN FROM THE LIVED EXPERIENCE OF
ASPERGER'S SYNDROME**

by

Craig Allen Talbot

A Dissertation Submitted to the Faculty of
San Diego State University and the University of San Diego
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

Dissertation Committee:

Douglas Fisher, Ph.D., San Diego State University
Nancy Frey, Ph.D., San Diego State University
Jerome Ammer, Ph.D., University of San Diego

January 2012

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DEDICATION

This study is dedicated most of all to my family for they have paid the highest price for this degree. Their support has been almost unwavering and after having an absentee father and husband for five out of eight years is an unbelievable sacrifice! Their home, their own educations, their own sacrifices have been endless. Three of my four children do not remember a time when I was not in school and have longed for the day when I would finish this degree. I could never have finished this without my wife's endless single-parenting and logistical skills.

For whatever reason I was led to perform this particular study, it was the catalyst for the diagnosis of my youngest son – and the LONG over-due application of understanding and logic to our own lived experience of Asperger's Syndrome. Finally, there is peace in our chaos.

Our ever-patient neighbors, friends and relatives have also paid a price along with us.

Val & Holly Johnson who not only lived their own experience, but knew how and when to step in and buoy up others in their time of need – going FAR beyond what friends would do! They bring the term “pay it forward” to life and make the “lived experience” bearable. They are ordinary people who do extraordinary things and allow others to dream big and make a difference in the lives of others on the spectrum. Every day, they show others what persistence can do and why it matters.

Finally, my parents who taught me to NEVER give up! My dad, who did not live to call me Dr. Talbot, but will proudly be looking down on graduation day. My mother is always fulfilled by service and project completion – no matter whose project. Her example propels me to keep going—no matter what. The way she has treated her brother with extreme Asperger's Syndrome without knowing what it was for 60 years displays her true character.

Most of all, the children on the spectrum! They are the reason for this and so many other studies. They struggle day in and day out. They are the true heroes. As we learn to become better teachers and motivators, the world becomes a far more fulfilling place for all of us. The potential for genius that has been locked behind gates of isolation for centuries is finally coming into the light. It is through the spirit of inclusion that this genius is being unlocked to benefit society as a whole. The last 60 years has paved an entirely new path and paved the way for a future that is bright and full of hope with ways to overcome the challenges that come with ASDs.

Not everything that steps out of line, and thus ‘abnormal’, must necessarily be ‘inferior’.

– Hans Asperger (1938)

Good parenting and good teaching haven’t changed that radically over time; it’s just that with a neurotypical child, you can get away with less effective parenting and teaching because the child will adapt to you, but with an ASD child, you need to be at the top of your game because the ASD child will not adapt to you, you need to adapt to them.

ABSTRACT OF THE DISSERTATION

What We Can Learn From the Lived Experience of
Asperger's Syndrome

by

Craig Allen Talbot

Doctor of Education

San Diego State University and the University of San Diego, 2012

The overall purpose of this study was to survey the personal experiences of individuals with Asperger's Syndrome (AS), analyze and combine them into a shared lived experience in order to provide information pertinent to treatment and intervention, particularly in educational and extra-curricular settings.

Those teaching, volunteering or working with individuals with AS must consider their behavioral propensities and natural inclinations in both characteristics and individual personality traits when guiding them in schooling, career preparation, life skills, social interactions and other responsibilities.

The goal of the study was to identify common interventions, including technology interventions, or patterns of behavior used by teachers, parents or other adult leaders that assisted AS youth to adapt to neurotypical environments at home, school and other extra-curricular settings. It was also assumed that the study would reveal deficits in leadership and preparation that might have had a more positive impact if the understanding of AS by these leaders had been more current and complete. It was also assumed that the study would likely reveal some consistency in the symptoms addressed by the interventions and patterns of behavior.

This study used a phenomenology method of research. Data was gathered from video monologues posted on YouTube by those with AS or parents of those with AS describing their own lived experiences involving AS. Data was analyzed primarily based on Colaizzi's *Treatment of Data* model. Twenty five subjects were selected based on their therapeutic interventions or interaction with parents, teachers or volunteer leaders: 13 were students who had AS and 12 were parents of children who have AS. The study did not include documentaries as a data source. Videos were transcribed word-for-word, then analyzed for patterns, topics and symptoms. Substantial, meaningful quotes were included in the findings following the phenomenology method of research. The data analysis found significant differences in the data gathered from parents of children with AS and students with AS.

The study produced 12 recommendations for parents, teachers and volunteer leaders to implement when working with young people with Asperger's Syndrome in educational or extra-curricular settings.

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ACKNOWLEDGEMENTS

I would like to thank my phenomenal chair, Dr. Douglas Fisher for his insight, honesty and encouragement over the past seven years! He has been, and continues to be an incredible inspiration to me. I would also like to thank my other committee members: Dr. Nancy Frey and Dr. Jerry Ammer. Dr. Ammer willingly agreed to join my committee late in the game. Dr. Frey spent many meticulous hours coaching me through the dissertation process. Their efforts are much appreciated.

My employer and colleagues at Invensys / Wonderware and Invensys Learning Services (formerly Wonderware Technical Training) who have allowed me to completed this degree and this study with no debt and with full office space and moral support day and night. Doris Alex signed on the dotted line for me to start the program and her support has never wavered.

My phenomenal editors Pam Pescara and David Berschauer who made sense out of nonsense and provided turn-around times that, at times, made my head spin. Their dedication to my success and to the good of both my family and the Asperger community is unbelievable and heartwarming. Pam's insight, caring and skills moved this project forward many times.

The SDSU/USD Joint Doc Cohort 3 and my beloved LA/OC carpool! This program would never have been the same without them – and I would never have gained the same experience without them. When I realized my original idea for a dissertation was completely out of scope, it was the carpool that brought this study to life – and Dr. Doug Fisher who gave it legitimacy. I said many times I felt as if I were going to school with my cousins. We had a cohesive group that brought engagement, enthusiasm and dedication. Professionals I am proud to have been associated with and even more proud to call my friends.

The professors throughout our Joint Doc program were fantastic! For the first time in my life, I was completely absorbed in learning; consumed and energized by the knowledge and the engagement with the learning of the group. Our professors were masterful at applying their own years of experience with the experience our cohort brought with us.

I also acknowledge to amazing impact of so many teachers, volunteers, therapists and others who have learned how to truly reach children with ASDs. We need more of them!!

CHAPTER 1

INTRODUCTION

Each child is born with a unique and distinct personality, but a brief perusal of any child development literature or parenting book will quickly orient you to expect specific skills at specific age spans; commonly referred to as developmental milestones (Bonvillian, Orlansky & Novack, 1983; Prudham, 2008). Developmental milestones are sets of functional skills or tasks that most children can do within a certain age range. Doctors, educators, social workers, and other professionals involved with children, use milestones to help assess development. While each milestone has an age span, the actual age at which a normal or “neurotypical” child reaches that milestone can vary.

Those who have spent large blocks of time with young children observe that through the uniqueness of each individual child, there is generally a sense of what is “normal” or “neurotypical.” Parents and others close to children often sense differences in children as young as two; often with no medical or psychological diagnosis of disabilities, simply a parental sense of something unusual.

BACKGROUND

The researcher experienced this sense of something unusual in his second son at around age two. He did not like to be hugged; would not go to sleep if he were held; he entertained himself without a need to be cared for by other people; his emotional responses were more like an on/off switch than a continuum; he broke everything; he would study things intently, then suddenly display acquisition of new skills, including speech well beyond expected milestones for his age. It was not until age seven that the researcher began to learn about something called Asperger’s Syndrome due to a cousin’s diagnosis. The more the researcher learned, the more Asperger’s Syndrome (AS) began to explain MANY of the behavior “differences” both parents observed, but could not explain – for five years. This led to much research and an eventual diagnosis from a pediatric neurologist – and a “lived experience” of AS. More importantly, it led to a quest to find out what professionals and

parents alike had discovered to help those with AS brain wiring succeed in a neurotypical world.

Barbara Kirby, founder of the OASIS Asperger Web site and co-author of “The OASIS Guide to Asperger Syndrome” (Bashe & Kirby, 2005) shares her own story of the lived experience of AS and how the discovery of AS changed hers and her family’s lives forever.

Our son was eight years old in 1993 when we first heard the term *Asperger Syndrome*. We hadn’t heard it from any of the score of professionals we had turned to for help throughout the years when we wondered and worried about his particular difficulties and differences. Instead, a friend who knew something about autism had the courage to hand us a copy of a relatively new publication, *Autism and Asperger Syndrome* by Uta Frith, and say, “Please read this. It reminds me of your son.”

When I put down the book, I knew I had found an explanation that finally made sense. It helped me to understand that what was happening to my son and to our family wasn’t his fault or the fault of my parenting—as so many people, professionals, friends, and family members had so hurtfully suggested. He was not a “bad” child and we were not “bad” parents.

I would like to say that when I finally learned the news, I hit the ground running. But that would be a lie. What really happened is I hit the ground with a huge splat. I can’t ever remember being so frightened. My son, whom I loved more than anything in the world, had a problem that could not be fixed even if I would only relax, stop hovering, discipline him properly, stop trying to be his friend and act like a mother, pay more attention, pay less attention, spank him—or follow any of the other “helpful” suggestions offered to me by well-meaning professionals, family, and friends. Certainly none of them ever suggested that my son’s problems stemmed from a neurological disorder about which no more than a handful of people around the world knew anything.

Though I’ll never forget the pain of those comments, I’ve learned that there was nothing in my advisors’ personal experience that could have allowed them to understand that my son’s behaviors were anything other than the result of incompetence—ours at parenting and his at being a “good” boy. They simply did not know. As I soon learned, there was a world of “experts” out there who knew just about as much. Or as little.

You would think that finding a name for our son’s behaviors would translate into finding some help and answers. But you would be wrong. Our son’s doctor had never heard of Asperger Syndrome, neither the library nor the bookstore had a book on it, the local autism group had “heard” of it but did not have any information, and when I called local hospitals, they told me that the condition was rare and they had never seen a child with the diagnosis. How was this possible?

The realization that we were alone with this disorder, diagnosis, whatever it was, induced a level of fear and frustration that after all these years I still cannot explain. Perhaps it's something only another parent in exactly the same position can understand. ...

My son's teachers were more than willing to help, but they were also in the dark. After all, they weren't trained to deal with students like him. Looking back, I am amazed at how hard they worked at understanding and supporting my son. Still, I cried—and I continued to cry for a very, very long time. (Bashe & Kirby, 2005, pp. 1-2)

Much has changed since 1993. There are websites, books, support groups social media communities, technology interventions and medical journals containing information about AS. Most medical and psychological professionals are now familiar with the condition and some specialists are armed with treatment programs and ideas for therapy. Yet the helplessness that Barbara Kirby described is just as current and frustrating for most parents today as it was for her in 1993. Some parents may lack the resources to get a proper diagnosis, and even with a neurological diagnosis, do not get informed advice. In many instances, parents are still encouraged to control the child through ineffective disciplinary measures. Educators are often at a complete loss how to meet the needs of an AS youth even when made aware of the diagnosis. The number of clinical psychologists prepared to assist these families is surprisingly small – and getting an appointment with a real expert can take several months and many experts do not accept health insurance (Blue Shield of California, personal communication, September 27, 2011; G. Grover, personal communication, personal communication, September 20, 2011; P. Passaro, personal communication, August 31, 2011). Even well informed parents often feel like banging their heads mirroring an autistic tantrum of their own.

What is Asperger Syndrome?

The most commonly used diagnostic criteria used in the United States is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (commonly referred to as the “Diagnostic Bible” of the American Psychiatric Association) (American Psychiatric Association [APA], 2000). The most commonly used criteria in Europe and Australia is by Gillberg (Gillberg, 2002; Gillberg, 1989; Szatmari, Bremner, & Nagy, 1989). The detailed diagnostic criteria for both the DSM-IV and Gillberg are listed in Chapter 2. The major aspects of the diagnostic criteria are summarized here:

- Impairment in social interaction, including nonverbal behaviors and peer relationships
- Repetitive patterns of behavior and activities coupled with intense interests, including restricted interests and abnormally intense focus and unusual adherence to routines
- Impairment in social, occupational or other important areas of functioning
- Typically no delay in language development
- Typically no significant delay in cognitive development or age-appropriate self-help skills
- No diagnosis for another specific Pervasive Developmental Disorder (PDD) or Schizophrenia

What Asperger Studied

How did this condition come to be diagnosed and why is it labeled with such an unusual name? Hans Asperger was a pediatrician in Vienna, Austria in the 1930's (Attwood, 2007). Dr. Asperger held a strong belief that "unusual" did not equal "inferior" with regards to children's behavior. In Nazi-occupied Austria, he studied young children with what today could be termed "quirky" personalities and advocated that education 'will render harmless the dangers which are a child's genetic disposition' (Attwood, 2007, p. 10). Most of his studies were hidden away in the late 1930's. The condition he observed and documented later became known as autistic personality disorder and eventually in 1981 became known as Asperger's Syndrome (AS) (Attwood, 2007; Wing, 1992). It was not until the late 1990's and even into the 2000's before AS became well known in the English speaking world.

Dr. Asperger wrote descriptions of children's difficulties in three major areas of behavior: communicative, social, and functional (Asperger, 1944/1991). This is now referred to as the "Triad of Impairment" (Bashe & Kirby, 2005). There are frequently motor and sensory difficulties, as well. However, some of the behaviors, while not neurotypical, displayed as abilities that were extraordinary or highly gifted.

COMMUNICATIVE

Dr. Asperger noted many differences in the children he studied and how those differences impacted their relationships with others. "How odd is his voice, how odd his manner of speaking and his way of moving. It is no surprise, therefore, that this boy also lacks understanding of other people's expressions and cannot react to them appropriately" (Asperger, 1944/1991; Hipplier & Klicpera, 2004).

SOCIAL

Simon Baron-Cohen (1995) proposes that the “Theory of Mind” has a tremendous impact on one’s ability to interact socially with others. The Theory of Mind (ToM) is the ability to recognize and understand thoughts, beliefs, desires and intentions in ourselves and in others. It enables us to understand, and interpret behavior, and often predict what others are going to do next. It has also been described as ‘mind reading’ or ‘mind blindness’ (Baron-Cohen, 1995) or, colloquially, a difficulty in ‘putting oneself in another person’s shoes’. A synonymous term is empathy (Gillberg, 2002). The child or adult with Asperger’s syndrome does not recognize or understand the cues that indicate the thoughts or feelings of the other person at a level expected for someone of that age (Attwood, 2007; Frith & Happe, 1994). Those with Asperger’s Syndrome have all the feelings of empathy, but tend to have a muted ability to recognize and perceive the triggers to initiate feelings based on experiences of other people (Ramachandran, 2011; Robison, 2011).

Another neurological term is impaired executive function. This impacts the child’s ability to learn from previous experience. It becomes more apparent as the students’ curriculum becomes more complex and self-directed. The (AS) students appear to have cognitive abilities below their peers (Attwood, 2007). This seems paradoxical with many AS students having above average intelligence.

FUNCTIONAL

One consistent pattern he observed was a delay in social maturity and social reasoning. The children he observed had difficulty making friends and were often teased. There were impairments in conversational language. Often, the grammar and vocabulary were advanced, but there was something unusual about their ability to have a conversation expected for their age [at any age]. There were conspicuous impairments in the communication and control of emotions. Empathy was not as mature as one would expect based on the child’s intellectual abilities. They frequently had an egocentric preoccupation with a specific topic of interest that dominated their thoughts. Many had difficulty maintaining or shifting attention. They often needed more help with organizational skills from their mothers than one would expect. He described clumsiness and a strange gait when

they walked. Many of the children displayed extreme sensory issues to particular sounds, smells, textures and touch (Attwood, 2007).

Asperger found disturbances in active attention in autistic children and a number of subsequent studies have suggested that at least 75% of AS children have a profile of learning that corresponds with an additional diagnosis of Attention Deficit Disorder (Attwood, 2007).

People with AS can typically focus for long periods at a time. This attention issue causes considerable problems when switching thoughts to a new activity, especially without closure on the last topic. Many times the children appear to resist change because they are not allowed to transition from one activity to the next and the change was unexpected or too abrupt (Attwood, 2007).

MOTOR AND SENSORY

Difficulty maintaining eye contact is a symptom that is noted in virtually every study of AS. This difficulty manifests itself in many social settings, but is particularly troublesome in a school setting. Unlike a neurotypical person who intuitively integrates eye contact into concentration and focus on the conversation or teacher's lecture, for example, eye contact for a person with AS is an additional use of intellectual concentration (Attwood, 2007). This means that to many students, it's as if they are concentrating on two lectures at once; one to look at the teacher and one to listen to the subject matter being presented. This is exhausting and many students give up and quit doing both.

EXTRAORDINARY ABILITIES

Dr. Asperger also noted specific talents that could lead to successful employment. Some developed life-long relationships (Attwood, 2007). Many had above average intelligence and could focus on their specific area of interest for long periods of time, thereby developing skills in certain areas mature beyond their age. While this may amplify their social deficits further, it may also provide a path to excellence in employment.

Impact of Asperger Syndrome

These behaviors not only impact AS children themselves, but immediate and extended family members, friends, school teachers, sports coaches, church and scout leaders, and so on. AS children are often just as frustrated as the adults in their lives. They know

they are different, but they do not know why. For many, diagnosis of AS is a huge relief (Attwood, 2007; Hall, 2001; Jackson, 2006; Robison, 2007; Willey, 1999). Parents often hesitate placing a label on their child, but most find the explanation of different behavior based on different brain wiring rather than some oppositional defiance or disease to be quite relieving – especially when they learn to embrace the positive aspects of AS and work around the challenging aspects.

Prevalence of Asperger Syndrome

The number of documented cases throughout the world is increasing exponentially every year with many more cases suspected. Based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria (APA, 2000), the American Psychiatric Association estimates between 1 in 33,000 and 1 in 1200 children have AS. Clinicians in Europe and Australia find the Gillberg criteria to more closely represent the original descriptions of Hans Asperger and therefore deem it more reliable and accurate (Gillberg, 2002; Gillberg, 1989; Szatmari et al., 1989). Gillberg criteria estimates between 1 in 280 and 1 in 210 children have AS! (Attwood, 2007) Tony Attwood, a well respected and commonly cited author with many years of clinical experience regarding all aspects of AS, has the clinical opinion that based on the Gillberg criteria, we are currently detecting and diagnosing about 50% of children who have AS (Attwood, 2007).

Asperger Syndrome and Educators

The knowledge base about AS is growing, yet most educators of all grade levels know very little about AS and the simple adaptations they can make with their AS students. California teaching credentials currently require one semester course to cover all learning disabilities. Asperger's Syndrome is one of many such disabilities. AS is also a newly recognized disability, which means teachers who have had their credential more than a few years would never have been introduced to AS during their own teacher preparation.

An AS university student in the UK related a personal experience regarding interactions with his professors his freshman year. Christian [pseudo name] is a brilliant musician, but shows some of the delay in social maturity Dr. Asperger saw in his research subjects decades ago (C. Christodoulou, personal communication, November 18, 2009). He

also had the intense focus in a favorite area of interest often seen with AS. He had no problem practicing his instrument many hours per week and thrived in an environment where he could perform with other skilled musicians. His challenges came from not being able to interpret the social and instructional clues from his professors. He found himself over-reacting and having conflicts with them. He accused them of being unfair to him and did not have the eye contact and social quickness to speak to them face-to-face without himself or the professors becoming frustrated or angry.

One of his professors knew about AS and when Christian told him about his condition, he began to approach him differently. Their relationship took on a much more positive direction. Another of his professors had never heard the word “Asperger” and did not have a clue what it meant or what it had to do with what he perceived to be a short-tempered annoying student. When Christian gathered his thoughts enough to explain the basic idea of AS, the professor said he was willing to learn about it. By this time, it was nearly summer break, so Christian wrote down some information about AS and provided his professor with several internet links to videos that would orient him to the condition. When he worked with his professors one-on-one and they had an understanding of his condition, he was able to excel and avoid needless conflict. His experience as “just another college student,” however, yielded a much less positive outcome and revealed a significant void of knowledge in the faculty regarding AS (C. Christodoulou, personal communication, May 3, 2010).

One high school teacher had a 9th grade student whose pseudo name is Julie. Julie was not focused on the class lectures at all. In addition, she had no social “filter” and would make comments out loud that were distracting and off topic. This would often result in embarrassing situations for her and irritation for her teacher. After some research, her teacher learned that her numerous attempts to have Julie “look at me” might have been contributing to the problem. She decided to try an experiment and have Julie near the front of the room and doodle in a notebook during class lectures. The teacher was rather strict and was not accustomed to having students even appear distracted. She was amazed when each and every time she called on Julie for an answer, Julie provided the correct answer. While Julie appeared to be off in another world, she was far more focused on the lecture and the conversation in the room than she had been at any time in the previous weeks. This simple

adaptation after understanding Julie's condition brought her grade up substantially, saved frustration for the teacher and eliminated the embarrassing outbursts in front of the other students (M. Belfield, personal communication, February 29, 2008).

Statement of the Problem

Due to the prevalence of AS, many people from all walks of life come in contact with individuals with AS. Some contact is made through neighbors, jobs, schools, sports organizations, scouting, etc. Most neurotypicals don't know much about AS and don't understand the behaviors resulting from the condition. With this lack of understanding often comes a view of the resulting behaviors through a lens of deficits – and a level of frustration for everyone involved when the AS individual is not able to adapt their behavior to the expectations of the uninformed neurotypical.

PURPOSE OF THE STUDY

This study is intended to lead to an empathy and an understanding of what it is to live as an “Aspie,” as those with AS are sometimes referred; then to describe the things that teachers and intuitive parents figured out and did to guide young people with AS through the neurotypical world successfully. This and other studies in the future can help teachers, parents and volunteer leaders embrace and encourage the positive aspects of AS individuals while lessening the frustrations and challenges of the differences between AS and neurotypical individuals. This researcher hopes that empathy and understanding woven into the lived experience will lead to the creation of tools and the dissemination of information to those parents, teachers and volunteer leaders who can then embrace the difference of AS in positive ways on an individual level. Based on the evidence available, it is the researcher's belief that if the neurotypicals can adapt to those with AS during their youth, those with AS will find many more bridges into the world of the neurotypicals one interaction at a time. The vast array of literature in less than two decades tells us the researcher is not alone on this quest.

A FOUNDATION ON WHICH TO BUILD

Peter Szatmari is a professional psychologist who has been working effectively with children with ASDs for over twenty years. Dr. Szatmari has keen instincts and has

performed many research studies, written many books and journal articles. His writing is heart-felt and insightful. He offers much advice and hope to those on the Autistic Spectrum and their families.

My clinical practice over the last twenty years has been devoted exclusively to diagnosing and assessing children with ASD [Autism Spectrum Disorder] and to helping parents, teachers, and the children themselves cope, come to terms with, and sometimes even celebrate, the predicaments associated with ASD. My frustration at not knowing enough has also encouraged me to do research into the causes of autism, into what Asperger syndrome looks like, how it differs from autism, and how children with ASD change over time through adolescence and into adulthood. I have seen some individuals with ASD become mature and articulate adults and have seen others struggle with significant and heart-wrenching difficulties. When I look back over those twenty years and try to single out the most important ingredient associated with a successful outcome, I come back, time and again, to the importance of having a family or a teacher understand what it's like to be inside the mind of a child, and that leads to the development of a special relationship without which any intervention program is bound to fail. (Szatmari, 2004, p. x)

“It all depends on the way you see things,” ... “Once you understand how they think and see the world, what can seem like a disability one day can be a talent, or a gift, on another” (Szatmari, 2004, p. vii). Taking the time and effort to look at the world through the lens of the ASD child – and adapting our approach to them in truly the only hope of long-term successful interventions and adaptations. Not surprisingly, it's simple. However, just because it's a simple concept does not make it simple to live. Viewing life through the ASD lens creates empathy; empathy creates patience; patience allows for understanding; understanding allows relationships to develop. As Dr. Szatmari so eloquently wrote, that is when interventions succeed.

CHAPTER 2

REVIEW OF THE LITERATURE

To establish a framework from which to investigate “the lived experience of Asperger’s Syndrome,” through accounts of actual interventions and methods of assisting individuals, this review of literature examines both the diagnostic and medical aspects of Asperger’s Syndrome, and biographical illustrations of true lived experiences.

The methodology of “Lived Experience” is distinct from other research approaches in that it focuses on the everyday encounters and interactions, as experienced by the individual. It is both biographical and subjective; two attributes that are often ignored or purposely eliminated from many studies, which look for generalizations that can be applied to the whole body of research or behaviors.

Yet, it is precisely the uniqueness of individuals with Asperger’s Syndrome, and his or her corresponding narrative that provides information that cannot be elicited through traditional human science investigative tools, such as surveys, controlled experiments, and scripted interviews. Also, many of those techniques could provoke upsetting behavior in the subjects by inherent triggers that researchers may not be familiar with.

This “lived experience” information is especially important when investigating behaviors, like Asperger, because it is the only methodology to provide both context and comment. Both of these perspectives are essential in understanding personal aspects of the Asperger individual’s situation, evaluating the impact, and using that information to develop strategies.

This literature review will be used to support a phenomenological study and will integrate extensive passages from authors who shared their own lived experiences regarding Asperger’s Syndrome and the impact it has had on their lives. It is of value to note that many of the expert researcher writers in the field of autism and Asperger’s Syndrome have children of their own on the autistic spectrum.

WHAT IS ASPERGER SYNDROME?

Asperger Syndrome is a neurological disorder characterized by what psychiatrist Wing terms a “triad of impairments affecting: social interaction, communication, and imagination, accompanied by a narrow, rigid, repetitive pattern of activities” (Bashe & Kirby, 2005, p. 9). First described in “Autistic Psychopathy” by Hans Asperger, published in 1944, it did not become widely known until Frith translated the paper from German to English in 1991 (Asperger, 1944/1991).

ASPERGER’S ORIGINAL DESCRIPTION

Asperger could not find a description or explanation for the small group of similar and unusual children that he found intriguing. He suggested the term *Autistische Psychopathen im Kindesalter* (direct translation: Autistic Psychopaths in Childhood). A modern translation of the original German psychological term ‘psychopathy’ into current English terminology would be personality disorder – that is, a description of someone’s personality rather than a mental illness such as schizophrenia (Attwood, 2007).

Pervasive Development Disorders

Asperger Syndrome (AS) shares many qualities with a collection of disorders classified together as *pervasive development disorders* (PDDs) (Tanguay, 2000). To date, there is no definitive known cause for either AS or PDDs.

Autism Spectrum Disorders

PDDs are increasingly grouped together under the term *autism spectrum disorders* (ASDs) (Bashe & Kirby, 2005). It is common to refer to people with any of these disorders as “on the spectrum” or “on the autistic spectrum.” It is also common to refer to more severe cases, or those with more notable disabilities as “farther onto the spectrum.” Asperger’s Syndrome is also referred to as “high functioning” autism (Attwood, 2007; Hippler & Klicpera, 2004; Wing, 1992) whereas “low functioning” is typically used to refer to more serious cases of autism are those displaying more serious language delays and often requiring more intensive interventions at younger ages.

AS differs from other PDDs in that those children who have it usually reach major developmental milestones on time or even early. In most cases, a child with AS appears to

be developing normally in terms of expressive speech, motor development, and may be “on schedule” for basic self-help skills, toilet training, self-feeding, and manipulation of common objects. The first sign of differences are often deficiencies in nonverbal language like pointing and eye contact, and a lack of interest in others around them. Parents typically become acutely aware of differences between their AS child and neurotypical children around pre-school age (Bashe & Kirby, 2005).

Asperger observed that the children’s social maturity and social reasoning were delayed and some aspects of their social abilities were quite unusual and less developed than their peers of the same age at any stage of development. The children had difficulty making friends and were often teased by other children (Asperger, 1944/1991).

IMPAIRMENTS

Asperger observed impairments in verbal and non-verbal communication in the children he studied, especially the conversational aspects of language. The children’s use of language was pedantic, and some children had an unusual prosody that affected the tone, pitch and rhythm of speech. The grammar and vocabulary may have been relatively advanced, but at the end of the conversation, one had the impression that there was something unusual about their ability to have a typical conversation that would be expected with children of that age (Attwood, 2007; Wing, 1981).

ASPERGER’S OBSERVATIONS

Asperger also observed and described conspicuous impairments in the communication and control of emotions, and a tendency to intellectualize feelings. Empathy was not as mature as one would expect, considering the children’s intellectual abilities. The children also had an egocentric preoccupation with a specific topic or interest that would dominate their thoughts and time. Some of the children had difficulty maintaining attention in class and had specific learning problems. Asperger noted that they often needed more assistance with self-help and organizational skills from their mothers than one would expect. He described conspicuous clumsiness in terms of gait and coordination. He also noted that some children were extremely sensitive to particular sounds, aromas, textures, and touch. Asperger theorized that this combination of traits and the way they set the children apart

from others led to the excessive amount of bullying he observed with these children (Attwood, 2007).

Conversations

Children with AS are typically early talkers with sophisticated vocabulary and normal-to-high intelligence. A striking symptom of the syndrome is an obsession with particular subjects and knowledge of that subject far beyond their years. This often causes a tendency to talk endlessly about their passions and makes their speech more of a monologue than a point of entry to reciprocal conversation (Armony, 2008; Attwood, 2007).

Asperger had noted in the 1930's that those he studied often had advanced grammar and vocabulary, but no ability to converse normally as other children their age. Robison (2007), a person with AS, noted in his memoir that as early as four years of age he did not converse the same way other children did – and it made it extremely difficult for him to make friends. There were some challenging experiences at his pre-school, at his apartment building, at his local park and many trips back to the arms of his mother.

At first, I was excited. As soon as I saw the other kids, I wanted to meet them. I wanted them to like me. But they didn't. I could not figure out why. What was wrong with me? I particularly wanted to make friends with a little girl named Chuckie. She seemed to like trucks and trains, just like me. I knew we must have a lot in common. (Robison, 2007, p. 8)

John Elder had been taught specifically how to make friends with dogs, but had never consciously noticed there was a difference in the way people interacted with one another when they first met. He had missed the cues that many pick up on without being specifically taught.

At recess, I walked over to Chuckie and patted her on the head. My mother had shown me how to pet my poodle on the head to make friends with him. Any my mother petted me sometimes too, especially when I couldn't sleep. So as far as I could tell, petting worked. All the dogs my mother told me to pet wagged their tails. They liked it. I figured Chuckie would like it too.

Smack! She hit me!

Startled, I ran away. *That didn't work*, I said to myself. *Maybe I have to pet her a little longer to make friends. I can pet her with a stick so she can't smack me.* But the teacher intervened.

"John, leave Chuckie alone. We don't hit people with sticks."

"I wasn't hitting her. I was trying to pet her."

“People aren’t dogs. You don’t pet them. And you don’t use sticks.”
(Robison, 2007, pp. 8-9)

After “showing” Chuckie how to play with her toy truck in the sand box and having Chuckie leave without saying a word, John Elder just knew he had found the absolute correct way to make friends with her; by telling her about the dinosaurs he saw at the museum with his dad. He knew a lot about them and found them to be very interesting and he knew Chuckie would find them interesting too, but had no idea how to tell during a “conversation” if his assumption was true or not.

I walked over and sat down.

“I like dinosaurs. My favorite is the brontosaurus. He’s really big.”

Chuckie did not respond.

“He’s really big but he just eats plants. He eats grass and trees.

“He has a long neck and a long tail.”

Silence.

“He’s as big as a bus.

“But an allosaurus can eat him.”

Chuckie still didn’t say anything. She looked intently at the ground, where she was drawing in the sand.

“I went to see the dinosaurs at the museum with my dad.

“There were little dinosaurs, too.

“I really like dinosaurs. They’re neat!”

Chuckie got up and went inside. She had completely ignored me!

I looked down at the ground where she had been staring. *What was she looking at that was so interesting?* There was nothing there.

All my attempts to make a friend had failed. I was a failure. I began to cry. Alone in the corner of the playground, I sobbed and smashed the toy truck into the ground again and again and again, until my hands hurt too much to do it anymore.

At the end of recess, I was still sitting there, sitting by myself. Staring into the dirt. Too humiliated to face the other kids. *Why don’t they like me? What’s wrong with me?* That was where Miss Laird found me.

“It’s time to go back inside.” She grabbed my little paw and towed me in. I wanted to roll up in a ball and disappear. (Robison, 2007, pp. 9-10)

Between the ages of six and eight, however, John Elder had observed enough to learn some of the clues intellectually. In addition to a lack of instinct in picking up social and

conversational cues, the lack of practice due to social isolation further complicates the challenges AS children face when learning to converse.

I figured out how to talk to other children.

I suddenly realized that when a kid said “Look at my Tonka truck,” he expected an answer that made sense in the context of what he had said. Here were some things I might have said prior to this revelation in response to “Look at my Tonka truck”:

“I have a helicopter.”

“I want some cookies.”

“My mom is mad at me today.”

“I rode a horse at the fair.”

I was so used to living inside my own world that I answered with whatever I had been thinking. ... My new understanding changed all of that. All of a sudden, I realized that the response the kid was looking for, the correct answer was:

“That’s a neat truck! Can I hold it?”

Even more important, I realized that responses a, b, c, and d would annoy the other kid. (Robison, 2007, p. 20)

He also realized later in life that the coddling from adults who pretended they understood his conversation actually stunted his development. While it made his immediate experience more comforting, he learned more from the brutal honesty of the other children. He was constantly bewildered how the other kids learned how to communicate; and why he couldn’t.

How do normal kids figure this out? They learn it from seeing how other kids react to their words, something my brain is not wired to do. I have since learned that kids with Asperger’s don’t pick up on common social cues. They don’t recognize a lot of body language or facial expression. I know I didn’t. I only recognized pretty extreme reactions, and by the time things were extreme, it was usually too late. (Robison, 2007, p. 121)

John Elder had watched his parents talk to other grown-ups and figured he could talk to Chuckie and other kids the same way. But, as he puts it “I had overlooked one key thing: *Successful conversations require a give and take between both people.* Being Aspergian, I missed that. Totally” (Robison, 2007, p. 11). He gave up talking to kids and only tried to talk to adults for several years.

Temple Grandin had similar experiences to John Elder Robison, but overall had better success integrating with other children. She credits much of this success to the structured social expectations of the 1950's and 1960's and her mother's insistence on teaching (and drilling) her manners and social etiquette such as turn-taking, being fair and doing what others wanted. At times though, she still went on monologues about her own fixations. As John Elder noted, the other children taught her the appropriate parameters and inevitably the skills to judge for herself when enough was enough (Grandin & Barron, 2005).

One of the neighbors had a fake donkey where you'd push the ear down, the tail would go up and a cigarette would emerge from the donkey's butt. In the 50's, this was akin to a dirty joke. I thought that donkey was the funniest thing I had ever seen and I kept wanting to talk about it and talk about it and talk about it. The kids eventually go sick of hearing me go on and on, but what was good was that they just told me to stop. Plain and simple: "Cut it out; we're sick of hearing you talk about the stupid donkey." That definitely helped. People were pretty direct back then; the kids were direct and the adults were direct if you were doing something inappropriate. There wasn't a whole lot of explaining and trying to be sensitive about feelings. I was told, in very clear language, that my behavior was wrong ... (Grandin & Barron, 2005, p. 5)

Neurotypical children learn these kinds of social function skills – that also include how to join a conversation, personal space issues, and the importance of good grooming – at an early age and it is just as important that AS children learn them at the appropriate age span. When kids enter high school, the emphasis shifts to social skills that contribute to success in adult life: how to be an effective member of a study team, time management, dealing with co-worker jealousy, selling your talents, the hidden “rules” of the work place, etc. Early childhood social functioning skills need to be taught at an earlier age so higher-order social skills can be taught during high school (Asperger 1944/1991; Grandin & Barron, 2005).

As an adult, Temple Grandin enjoys friendships built on shared interest. Many times she shares rich conversations with friends on the autistic spectrum. She describes talking about things from the working of the brain to cattle to autism to their families, but as she puts it “We talk about all sorts of topics, but our conversations always have a purpose and usually take a logical path, we never talk just to talk” (Grandin & Barron, 2005, p. 29). Random chatting about random topics does not hold the attention of most AS individuals.

There are rare occasions when socially inappropriate behavior is not only tolerated, but fitting for the situation. One such occasion would be when Jesse Saperstein young man in his 20s with AS who completed the arduous 2174 mile, seven-month walk along the entire Appalachian Trail to raise money and awareness for a summer camp for children with HIV/AIDS. Jesse credits his ability to complete this journey to the gifts of AS: the intense ability to focus, the obsessive compulsive nature about one specific topic or activity for months or years at a time, the complete disregard for what others think about the activity, and so on. Jesse relays this experience of reaching the final summit at the end of his journey.

My father has lectured me on countless occasions, “People do not appreciate it when you impose yourself on their lives, Jesse!” But on the afternoon of Tuesday, October 11, 2005 ... all tact became null and void upon my reaching the summit of Mount Katahdin.

I took a few moments to admire the billowy, cumulous clouds hugging its jagged peaks before running my fingers over the plaque’s crenulated letters. Believe me, social graces were the last thing on my mind as a disposable camera was shoved toward weary day hikers who had no choice but to participate in my command photo shoot. A sardonic doppelganger of Kathy Griffin finally snapped, “What do you want now? Oh! You want me to hold the banner?! Fine!” The fiery redhead and I unfolded the banner signed by every Camp TLC camper. WE braced the mammoth ribbon against the wind, which seemed to assault us from all directions. Some man handed me a can of Budweiser line with condensation and said “Here! You’ve been walking for seven months and deserve this more than I do.”

I accepted it without hesitation. (Saperstein, 2010, p. 137)

Inappropriate Expressions

Attwood (2007) referenced Asperger’s description of impairments with control of emotion and empathy not being as mature as one would expect considering a child’s intellectual abilities. John Elder Robison (2007) tells of a time when he exhibited these tendencies with inappropriate facial expressions to the horror of his mother’s house guest.

One time, my mother had invited her friend Betsy over. I wandered in as they sat on the sofa, smoking cigarettes and talking.

Betsy said, “Did you hear about Eleanor Parker’s son? Last Saturday he got hit by a train and killed. He was playing on the tracks.”

I smiled at her words. She turned to me with a shocked expression on her face. “What! Do you think that’s funny?”

I felt embarrassed and a little humiliated. “No, I guess not,” I said as I slunk away. I didn’t know what to say. I knew they thought it was bad for me to be smiling, but I didn’t know why I was grinning, and I couldn’t help it. I didn’t feel joy or happiness. At the time, as I approached my teenage years, it was hard to figure out exactly what I did feel. And I felt powerless to react any differently.

As I left, I could hear Betsy. “What’s the matter with that boy?”
(Robison, 2007, p. 29)

Robison also had numerous frustrating situations with inappropriate expressions at school. He was criticized and ridiculed, and many times wanted to run and hide. Comments like “Why are you staring at me like that?” and “Wipe that stupid expression off your face! Right now!” and “You’re scary! You’re staring at me like a specimen in a jar!” were common. He not only heard the “specimen in a jar” comment from the students, but from his English teacher – numerous times; so many that it eventually led to him “offending” her with a somewhat psychotic answer as a defense mechanism that eventually lead to his dropping out of high school at age 15. He dropped out after numerous trips to the principal’s office, receiving straight F’s on a report card and then a 96% on his GED exam, highlighting the contrast between his intelligence and his ability to succeed in a neurotypical educational system. No adult or student ever attempted to obtain an actual answer as to why he was staring at them (Robison, 2007).

I don’t recall any grown-up ever trying to figure out *why* I was staring. I might have been able to tell them if they had asked. Sometimes I was thinking of other things and just gazing their way absentmindedly. Other times I was watching them intently, trying to interpret their behavior. (Robison, 2007, p. 89)

With no intuitive ability to interpret facial expressions, those with AS are forced to process them all intellectually. This is hard work and requires intense concentration (Baron-Cohen & Jolliffe, 1997; Klin, Jones, Schultz, Volkmar, & Cohen, 2002; Wing, 1992;). John Elder’s teachers in the 1960’s and 1970’s had no idea his intense staring was related to AS.

SENSORY ISSUES AND SOCIAL SKILLS

For individuals with AS and their loved ones, life presents a series of frustrations (Evans & Swogger, 2011). Perhaps the greatest one is learning to cope with the erratic yet constant emotional outbursts, forcing parents to play detective to their children’s behavioral triggers (Armony, 2008; Bauminger, 2002).

Discovering Sensory Overload

Hypersensitivity, especially in very young children, is one of the most unpredictable, individual and frustrating symptoms associated with AS. Children lack the intellectual development to know what is happening to them, and often the language skills to describe their frustrations to someone else. Something as simple as a clothing tag or a certain fabric can induce a full-blown, melt-down tantrum. A certain sound in a crowded room, for example, can seem as if it is amplified several times, inducing a tantrum because the child is utterly overwhelmed. What may seem like simple background noise to most people may seem like sirens blaring, and the child has no escape or relief (Grandin, 1995; Grandin, 2011; Robison, 2011).

It is equally frustrating for the adults who have no idea what is triggering the tantrum. These series of seemingly unprovoked melt-downs may go on for several years before the child is able to describe accurately what is happening to them. During early childhood, most parents have no idea this is a sign of AS and may not be empathetic. They are frustrated and often attempt to discipline the child back into “appropriate” behavior. The cycle repeats itself until the trigger is identified, and then a strategy is developed as to how to mitigate the triggers and the reactions to them (Attwood, 2007; Bashe & Kirby, 2005).

Max’s tantrums are “obscene,” says Arnold, yet the sensory stimuli that tend to make him most upset – bright lights, loud noises and large crowds – aren’t always the cause.

“There’s no formula, and that’s one of the most frustrating parts. I don’t know what to avoid,” she says.

Equally frustrating is the fact that “Aspies,” as they call themselves, are bright enough to realize that their limitations and impairments make them unlike their “neurotypical” peers, leading some to a life of isolation, low self-esteem, anxiety and depression. (Armony, 2008)

Temple Grandin’s mother was in tune with her daughter and learned early on to distinguish her personality from sensory overload. She maintained strict discipline and applied it consistently, but knew when it was appropriate not to apply it (Cutler, 2004).

She knew me well and she was a good behavior detective ... She understood the difference between behavior outbursts that resulted from me being tired, or from sensory overload (in those instances there wasn’t a consequence) and times when I wasn’t trying or was simply “being Temple.” I was often a willful child; autism

didn't compromise the very neurotypical way I tested boundaries to see how much I could get away with. (Grandin & Barron, 2005, p. 4)

Temple's mother did not use her sensory issues as an excuse to protectively isolate her. She had an innate sense that exposing Temple to many different experiences would prepare her for the future and enrich her life. She took her to eat in restaurants and expected her to use proper manners. She discovered Temple's areas of interest and used them as motivation to get her to learn new things. Temple credits her mother's strict expectations as a child for her ability to "fit in" to many social situations as an adult, but acknowledges that her mother had balance with those expectations.

She also knew I had problems with sound sensitivity and other sensory issues. For instance, if I had a tantrum at the circus she wouldn't have punished me for that, because she knew that I just couldn't tolerate the environment after a point. But she still took me to the circus, and other places, so that I gradually got used to them. I liked a lot of the things we did and because she knew me so well, I could try to enjoy them, trusting that when it got to be too much for me, she'd take me out of the situation. I give Mother a lot of credit for her acute understanding of my boundaries and when and how far she could push me. (Grandin & Barron, 2005, p. 9)

Sensory Overload Impact on Learning and Social Interaction

All learning stops during a tantrum. Most rational thinking also stops during a tantrum. Since sensory issues induce many of the tantrums in children, they will almost surely have an adverse impact on their ability to learn, including social skills. When teaching social skills to children, it is important to understand the impact that sensory issues have on a child's ability to learn and develop social awareness. When sensory and social overlap, learning will not take place. The sensory issues interfere with the child's ability to attend and learn. Anxiety of sensory issues can be acute and completely fill the child's field of awareness. Nothing else gets through (Grandin & Barron, 2005; Smith Myles, Tapscott Cook, Miller, Rinner, & Robbins, 2000).

Less severe sensory overload can also inhibit learning. Robison's (2011) sensitivity to fabrics often caused him to fidget and lose attention during school. His teachers were frustrated and angry with him, but he never thought to verbalize what was happening to him.

Things were worse when I was younger. There were days when a piece of clothing would bother me all day, and I'd just sit there distracted and fidgeting.

“Why are you squirming around like that?” my teachers would challenge me when they saw me wriggling. “Can’t you sit still?” I never knew how to answer them, so I’d say something like, “I don’t know,” and they’d just get mad at me. For some reason, I never thought to say what was really bothering me. I knew I was itching, but for some reason, I could never seem to say that. I should have said, “My sweater is scratching me and I’m distracted.” If I had, I’m sure my teacher would have understood. Maybe she’d have told me to take it off, or worked something else out. I wish I had known, but I just didn’t get it. (Robison, 2011, p. 166)

ENVIRONMENTAL INFLUENCES

Those teaching social skills to a child with an ASD must assess the environment from a sensory perspective and eliminate sensory issues that will impede the child’s ability to concentrate on the social lesson. For instance, if you are teaching table manners in a busy restaurant with a lot of noise and traffic, you are setting the child up for failure. Start with a meal at home where you can control the environment down to the lighting and background noise.

Parents and teachers scratch their heads, wondering why the child can’t learn basic social skills, or isn’t interested in even trying. What do they expect when the child is put into an environment that hurts? Fluorescent lights may be flickering like a disco dance-floor and the sound they make may feel like a dentist drill hitting a nerve. Could you learn under those conditions? (Grandin & Barron, 2005, p. 44)

ADAPTING TO SENSORY OVERLOAD

The more sensory issues that can be dealt with as children, the easier time ASD adults have fitting into adult roles in the neurotypical world. In many instances, it makes the difference between being able to maintain a job or not (Simone, 2010). When their sensory problems are not addressed as children or adolescents, they are often inhibited from fitting into everyday work situations. Some sensory overload happens so quickly and is such a constant part of their functioning that working in an office environment is impossible due to stimuli like telephones ringing, people talking constantly, the fax machine going, the smells of coffee, snacks, people eating lunch at their desks (Grandin & Barron, 2005). It becomes impossible for them to work (Bromley, Hare, Davison, & Emerson, 2004; Jackson, 2002).

Generally, reactions to sensory stimulation are managed better in adults with AS. Once they learn what they are sensitive to, they make modifications (AutismHangout,

2010a). They may wear comfortable fabrics, wear ear plugs in train stations, practice reactions to certain smells, etc. They are still hypersensitive, but they learn to mitigate the circumstances and control their reactions. Once parents of young children become aware of the sensory triggers, they can help in the same ways and likely avoid many of the melt-downs (Bromley et al., 2004; Cutler, 2004; Smith Myles et al., 2000).

John Elder Robison has taught himself to ignore sensory overload to touch, but even as an adult, he can feel the seams inside his shirts and pants. The tags on his shirt collars gnaw at his neck and he can even feel the label in his underwear. He understands clothing makers would not purposely incorporate sandpaper into the seams of their designs, but refers to it as a “constant assault.” Robison says that ignoring the sensory stimulus is most difficult in quiet moments when he is alone, but when he is focused on other activities, it has become much easier (Robison, 2011).

AS individuals at all ages find ways to comfort themselves and cope with their sensory issues. Kenneth Hall (2001) says he can spend entire days in his sleeping bag. He has curtains all the way around his bed to create a cozy place where no one disturbs him.

John Elder Robison piled pillows on top of himself as a child and still does as an adult. “I liked squeezing myself up tight in a tiny ball when I was little, hiding where no one could see me. I still like the feeling of lying under things and having them press on me. Today, when I lie on the bed I’ll pile the pillows on top of me because it feels better than a sheet. I’ve heard that’s common with autistic people” (Robison, 2007, p. 257).

As an independent adult, Temple Grandin (1995) built herself a “squeeze machine” that she modeled after mechanisms in cattle feed and milking yards to keep the cows calm. She had always liked being squeezed, but did not like people touching her and decided it may help to calm her in the sanctuary of her own home. It turns out to be one of her favorite places to get away from the world.

Sean Barron (Grandin & Barron, 2005) found it extremely difficult to concentrate for any length of time in the first and second grades. He also found it excruciating to sit for long periods. Although his teacher did not understand his behavior at the time, he managed to find a way to calm his senses by sharpening pencils.

The antidote to my problem was perched on a wall in the back of the room. For much of the 1969-70 school year, I must have carried with the pencils that were

sharper than Einstein because I spent an inordinate amount of time using the manual pencil sharpener. This behavior was a major source of irritation to Miss Johnson and was perceived by her as a violation of classroom rules. But from my socially-limited, perfectly self-relevant perspective, getting up to sharpen already pointed pencils gave me a break from endless sitting and focus and allowed me to derive comfort by engaging in, and being mesmerized by, the repetitive, slow-spinning movement required to turn the crank. (Grandin & Barron, 2005, p. 63)

As neurotypical adults become more aware of the hypersensitivities of AS, they can assist in channeling behaviors appropriately and empathize when AS individuals find methods that work for them – no matter how “different” they may appear (Pyles, 2002).

STRENGTHS / GIFTS

With so much emphasis on the impairments of the AS “disorder” and the accommodations necessary in the school system, the positive aspects of AS are often overlooked. While most neurotypicals are busy meeting the social needs of one another, those with AS are generally busy concentrating on their own interests. Dr. Asperger discovered early on that most of the children he studied had passionate interests in one or two subjects. This passion drove them to obtain vast knowledge about these topics, no matter whether the interest was shared with other people or not. They concurrently avoided learning about topics that did not interest them while absorbing comprehensive knowledge of other subjects (Gillberg & Gillberg, 1989; Wing, 1981).

We know an autistic child who has a particular interest in the natural sciences. His observations show an unusual eye for the essential. He orders his facts into a system and forms his own theories even if they are occasionally abstruse. Hardly any of this he heard or read, and he always refers to his own experience.

There is also a child who is a ‘chemist’. He uses all his money for experiments which often horrify his family and even steals to fund them. Some children have even more specialized interests, for instance, only experiments which create noise and smells.

Another autistic boy was obsessed with poisons. He had a most unusual knowledge in this area and possessed a large collection of poisons, some quite naively concocted by himself. He came to us because he had stolen a substantial quantity of cyanide from the locked chemistry store at his school.

Another, again, was pre-occupied by numbers. Complex calculations were naturally easy for him without being taught. (Asperger 1944/1991, p. 72)

Temple Grandin (1995) has the ability to think like a video camera and almost literally transfer her visions directly onto blue prints. John Elder Robison (2007) can convert

calculus equations into descriptions of sound and then use his intense power of concentration to physically modify an amplifier to make a guitar match that description. Luke Jackson (2006) applies his intense power of concentration and obsessive interest in computers to fix them and assist adults with applications and repairs at an age when most of his peers use computers only to play games or for forced homework assignments. Daniel Tammet's (2006) ability to see abstract symbols and numbers as shapes and colors helped him learn the Icelandic language in a week. There are AS musicians who can practice for hours on end and arrange complex music and others who can read all seven "Harry Potter" books in 11 days.

By taking advantage of the AS child's extraordinary capacity for visual learning, informed teachers can make learning and participation in school both therapeutic and an opportunity for growth. The teacher is able to see the autistic disability as a gift, as a talent to be encouraged, not as a symptom to be eliminated. This insight comes from a profound respect for the mind of the child with ASD and an intuitive capacity for understanding and imagining the mind of other people. The potential for learning is remarkable (Szatmari, 2004).

One 13-year-old was invited to attend a summer medical school workshop on electronic prosthetics (bionic arms and legs) after a relative saw him tinkering with an electronic device he had designed and built to detect floods in his grandparent's basements. The young man was speechless at the invitation and it turned out to be exactly what he needed intellectually. He found he fit in well – and no surprise, he performed at the top of this medical school class (Irvine, 2011).

Sometimes the gifts and intense learning are combined with the impairments and lack of awareness of the social and communication clues that neurotypical people easily interpret. Learning to coach the AS individuals to interpret the clues is crucial to their own ability to fit in. Helping more neurotypicals to get past the annoyance of the "sameness" and enter the world of the genius is also crucial to coaching them appropriately to place the proper value on their knowledge and understanding of their favorite topics. This will help them figure out how to balance the amount of knowledge to share with others. Stephen's interest in wasps has taken his knowledge past the passing sameness the average person has for a wasp and transformed it into a level of genius with his intimate understanding of the details missed by most. It took time, but he eventually brought his parents into his world of genius with him.

Stephen has been interested in wasps for several years. This is not just a passing fancy or a hobby that he finds amusing or that fills in the time between episodes of his favorite TV shows. He is obsessed with wasps, passionate about them. He talks about them all the time, with his teachers, his parents, and grandparents, even with complete strangers. If people show little interest, he chatters on, unaware of the boredom or frustration experienced by his listener. In the summer, he only wants to go to the park or the garden center to chase wasps around the plants and bushes and try to catch them. If, for some reason, his parent cannot take him there, he becomes very upset. Of course it's difficult for him to have a friend over to play since other children are afraid of wasps and do not want to be stung. Stephen has been bitten several times, but this in no way diminishes his enthusiasm. He catches wasps in a bottle and then releases them in his bedroom and enjoys watching them fly around the room, listening to the sound their legs make as they fly through the air, as I now learn. During winter, when the wasps go into hibernation, he spends hours in his room, poring over his collection of wasps encased in epoxy.

At first Stephen's parents were completely bewildered by his interest in wasps and not a little upset. After all, nine-year-old boys should be interested in sports, in toys that shoot and dart about. How could anybody find wasps enchanting? But now they find Stephen's interest charming. They too have acquired a detailed knowledge of the wasp's habits and lifespan. The four of us sit and talk about wasps as if we are all entomologists attending some esoteric conference about the mating habits of the yellow jacket. Stephen's disability has transformed us all, me for a moment, his parent for a lifetime. (Szatmari, 2004, pp. 3-4)

Stephen didn't just wake up one day obsessed with wasps, but, like many on the autism spectrum, his interests followed a pattern. Things that bored many people, he found fascinating and intriguing to the point where he passed their sameness and entered a world where he figured out how they all worked.

Stephen's interest in wasps was just one of a long line of special interests and preoccupations. The first consisted of very simple visual stimuli: water going down the toilet, looking through holes, dropping sand, wobbling antennae, and bouncing balls. As he matured, the interest became more complex (the moon, vacuum cleaners, and wasps), but all shared the quality of variation in shape, movement, color, and pattern. Sometimes the visual stimuli were accompanied by sounds – simple humming noises and the sounds wasps make when they fly. Shapes, movement, patterns, and sounds never lost their immediacy and the magnetic appeal for him. Stephen, it seemed, had a fit for not being easily bored by the simple things of life. (Szatmari, 2004, pp. 5-6)

John Elder Robison (2007) had had many obsessions as a child, but the entire course of his life was altered one Christmas. "Until my thirteenth Christmas, I studied rocks and minerals, dinosaurs, the planets, ships, tanks, bulldozers, and airplanes. That Christmas, I got

something new: an electronics kit!” He had to put it together himself and soon realized he had a true affinity for it – and an emotional connection to machines – without the danger of human interaction.

Machines were never mean to me. They challenged me when I tried to figure them out. They never tricked me, and they never hurt my feelings. I was in charge of the machines. I liked that. I felt safe around them.

Many people with Asperger’s have an affinity for machines. Sometimes I think I can relate better to a good machine than any kind of person. I’ve thought about why that is, and I’ve come up with a few ideas. One thought is that I control the machines. We don’t interact as equals. No matter how big the machine, I am in charge. Machines don’t talk back. They are predictable. They don’t trick me, and they’re never mean.

I have a lot of trouble reading other people. I am not very good at looking at people and knowing whether they like me, or they’re mad, or they’re just waiting for me to say something. I don’t have problems like that with machines. (Robison, 2007, p. 12)

Robison’s electronics kit for Christmas at age 12 led to a long and intimate relationship with electronics – and a relationship that was intensely focused on music and sound equipment. What started with a summer’s clumsy attempt at playing the bass guitar, led to rebuilding a Fender amplifier combined with old television parts. As a teenager, he was able to take math calculations from failed classes and add knowledge from college level text books; then test out his new inventions with local musicians who absolutely loved his modified equipment. His reputation spread and requests came for every kind of sound for every kind of instrument. Robison was able to translate terms like “This sound is fat” into “There’s a lot of even-harmonic distortion.” After failing in the school system, he knew how to visualize the circuits and how his complex calculus functions would change the raw sound coming in and going out (Robison, 2007). He describes his own ability due to an extraordinary ability to focus. He did not realize at the time that he was doing anything unusual or anything everyone else could not do. He only knew what he was doing in his own world and was unaware this intense power to concentrate was a gift.

I developed the ability to translate those waves I saw in my mind into sounds I imagined in my head, and those imagined sounds closely matched what emerged from the circuits when I built them.

No one knows why one person has a gift like this and another doesn’t, but I’ve met other Aspergian people with savant-like abilities like mine. In my opinion, part of this ability – which I seem to have been born with – comes from

my extraordinary powers of concentration. I have an extremely sharp focus. (Robison, 2007, p. 65)

Every adolescent needs to know their own value in order to build self-confidence, but with the list of impairments and challenges associated with Asperger's Syndrome, this becomes even more important. Once John Elder began to develop his gift with musical sound equipment, his life took an extremely positive turn.

I spent my free evenings at local concerts, and became part of the scene. Club owners, bouncers, and even bartenders began to recognize me; musicians talked to me and everyone seemed to respect me. I felt good about myself, and I felt even better when I discovered that many of them were misfits like me. Maybe I had finally found a place I'd fit in. (Robison, 2007, p. 65)

Robison also worked in the local audio visual department of the local junior high school. He started out fixing record players and when the advisors realized his gift, he soon repaired the tape players, movie projectors and anything else they could come up with that was broken. He loved the fact that he learned something from each thing he repaired that he could apply to his amplifiers. He also loved the respect from the adults he had never received before.

For the first time in my life, I was able to do something that grown-ups thought was valuable. I may have been rude. I may not have known what to say or do in social situations. But if I could fix five tape recorders in an afternoon, I was "great." No one except my grandparents had ever called me that before. (Robison, 2007, p. 65)

The intense focus and special interest of those with Asperger's Syndrome can be about anything. Temple Grandin (1995) is obsessed with cows. Daniel Tammet (2006) learns languages and memorized the number pi to 250,000 digits. John Elder Robison's (2007) friend Jim built a blast furnace at 18 in his parents' shed.

"Come check out what I built," Jim called and said one day. ... "That's my new furnace," he said proudly.

Another eighteen-year-old would have shown off his new car, or his new guitar, or his new camera. Jim showed off his new blast furnace. He had built the whole thing himself, right there in the shed. He had made the pliers and tongs and equipment to handle molten metal. He had made the frames to hold the ceramic furnace body. And he had made the burner. Amazingly, almost everything was constructed from scrap. I was sure there was nothing else like it in Amherst.

"You've got your very own steel mill," I said.

“No. It’s not a steel mill. You need oxygen injection to get the higher temperatures needed for steel. This is a nonferrous foundry for casting aluminum and bronze.” I was a good audience. The average layperson would not have appreciated the distinction. (Robison, 2007, p. 102)

Jim goes on to inform John Elder about the proper mixture of propane, signs of carbon monoxide, proper air flow when the doors were open or closed, melting chunks of aluminum and so on. While the majority of neurotypical teenagers would be focused on a myriad of things like college applications, members of the opposite sex, extra-curricular activities, and perhaps a part-time job, many “Aspergians” as Robison calls them, are focused intensely on one or two subjects that may not be interesting to the average person, but they obtain a knowledge equal to that of professionals with decades more “experience”.

The way these children perceive the world can change and transform the way we see the world and make it a more magical place, full of wonder and variety. Children with ASD can teach us about the infinite variety of sameness, and, seeing their diversity, we realize that there is a sameness to us all. Once we appreciate this, our attempts to help children with ASD accommodate to our world can be more successful and perhaps accomplished without the loss of their special gifts (Szatmari, 2004).

DIAGNOSIS

The challenge of recognizing and diagnosing AS is that it is entirely based on behavior. There are no sudden symptoms of illness like fevers or runny noses and it is often difficult to distinguish which behaviors are simply a child’s personality and which define him or her as having AS. Adding to this is the individual nature of the symptoms. Some symptoms, such as sensory overload, which may be known to those familiar with AS, are not recognized in various diagnostic criteria. This exclusion, however, does not mean they are less prevalent, less important, or have less impact on the person with AS (Bashe & Kirby, 2005; Rogers & Ozonoff, 2005; Wing, 1981).

There are two main diagnostic sources for Asperger’s Syndrome, or Asperger’s Disorder as it is referred to in the official manuals. The one most commonly used in the United States is the Diagnostic and Statistical Manual of Mental disorders, Fourth Edition (DSM-IV), commonly referred to as the “Diagnostic Bible” of the American Psychiatric

Association (APA, 2000). The one most commonly used in Europe and Australia is the Gillberg criteria (Gillberg, 2002; Gillberg, 1989; Szatmari et al., 1989).

DSM-IV Diagnostic Criteria for Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2) failure to develop peer relationships appropriate to developmental level
 - 3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - 4) lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - 1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - 2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - 3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - 4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia. (APA, 2000)

Gillberg's Diagnostic Criteria For Asperger's Disorder

- 1) Severe impairment in reciprocal social interaction (at least two of the following)
 - a) inability to interact with peers

- b) lack of desire to interact with peers
- c) lack of appreciation of social cues
- d) socially and emotionally inappropriate behavior
- 2) All-absorbing narrow interest
(at least one of the following)
 - a) exclusion of other activities
 - b) repetitive adherence
 - c) more rote than meaning
- 3) Imposition of routines and interests
(at least one of the following)
 - a) on self, in aspects of life
 - b) on others
- 4) Speech and language problems
(at least three of the following)
 - a) delayed development
 - b) superficially perfect expressive language
 - c) formal, pedantic language
 - d) odd prosody, peculiar voice characteristics
 - e) impairment of comprehension including misinterpretations of literal/implied meanings
- 5) Non-verbal communication problems
(at least one of the following)
 - a) limited use of gestures
 - b) clumsy/gauche body language
 - c) limited facial expression
 - d) inappropriate expression
 - e) peculiar, stiff gaze
- 6) Motor clumsiness: poor performance on neurodevelopmental examination
(All six criteria must be met for confirmation of diagnosis.) (Gillberg, 1991)

Because children with AS tend to show no cognitive or learning disabilities early on, the syndrome has long been misunderstood and misdiagnosed, and often confused with Attention Deficit Hyperactivity Disorder (ADHD) and other behavior abnormalities. AS kids seem normal, even gifted, until their behavioral oddities – recurrent tantrums, sensory

sensitivity, obsessive compulsiveness, anxiety and inability to focus – make them stand out (Armony, 2008; Church, Alisanski, & Amanullah, 2000; Perry, 2004).

Sometimes the differences in the behaviors are recognized by the children themselves. Kenneth Hall (2001) had just such a recognition about himself. He wrote an insightful book describing his experience – at age 10! He describes his recognition quite eloquently, especially for a 10-year-old.

When I was eight I found out about my Asperger Syndrome or AS and since then my life has changed completely. Before that life was very hard for me. I was always depressed. Life was depressing.

I always knew I was different and that I wasn't quite like other children. It's hard to say exactly how I knew. I detected some differences and I felt that things were not the same for me as for other children. Other children seemed to behave differently, play differently and talk differently, but I didn't know why. At that time, although I felt different I felt normal about being different. I thought I was the normal one and that it was the other people who were different, not me. Which is a perfectly feasible way of thinking. (Hall, 2001, p. 14)

For many parents, the fear of labeling their child often keeps them from seeking a diagnosis even when they suspect AS and know for certain there is something different about their child. But for AS children, like Kenneth Hall the diagnosis brought relief and clarity to his situation.

When I heard that I had AS I was very pleased because I had been wondering why everyone else seemed to be acting strangely. So I felt a bit relieved.

My life has been completely changed now and I am much happier. Things are much better and I understand myself better than I used to. Children with AS can do very well if they have a positive attitude, but they also need a lot of positive things around them and this is mostly up to the adults.

People help me and treat me better now. ...

... Another thing which has helped me a lot is Applied Behavioural Analysis, or ABA. This works by breaking goals down into small steps with rewards like tokens and prizes for each one. It is really good fun.

I like being different. I prefer having AS to being normal. I don't have the foggiest idea exactly what it is I like about AS. I think that people with AS see things differently. I also think they see them more clearly.

When I first heard I had AS I was sure God must have had a reason for making me different. I am still convinced about this. I also wondered what was God's special mission for me. I was quite determined to find out and I still am. Perhaps writing this book is part of it but I don't know. (Hall, 2001, pp. 14-16)

The common positive impact of diagnosis is true in almost every case no matter what age or what fear parents had of a label. Luke Jackson (2006) is another young man with an ability to share great insight at a young age. His book, *Freaks, Geeks & Asperger Syndrome: A User Guide to Adolescence* written when he was 13-years-old, offers a unique perspective of the autistic spectrum. He grew up in a family of seven children. Luke has AS and two of his brothers are autistic, one of them quite far onto the spectrum, or more seriously impaired with autism. He shares Hall's opinion about knowing the reality of what one is facing.

Many people can struggle on for years and years without ever getting a diagnosis of anything at all. I am one of the lucky ones who got answers to the questions Mum was asking (though she didn't tell me!). No one wants to have a syndrome and no one wants to tell people that they have got one, so sometimes things get left unsaid or not even thought of in the first place. This is not the best way at all. (Jackson, 2006, p. 26)

Societal norms are a challenge to overcome, but setting realistic expectations as early as possible lowers anxiety and creates a reality base from which to start where children can live up to the expectations around them.

... if the world in general does not understand or accept that people are all different, then people with AS are reluctant to tell others about it for fear of being considered a freak. After all, no one wants to be treated as if they have some contagious disease. These things then go unmentioned and people stay nervous and uncomfortable around someone who is seen to have a disability, especially when it is an invisible one. The people with the disability learn to keep quiet and struggle on; the doctors and the rest of the world therefore learn nothing – and so it goes on!

The best advice I would give to parents that have found out that their child has AS is just to accept them as they are. Preconceived ideas are never a good thing. To be on the autistic spectrum is not the same as being on death row – it is not a death sentence, it is not terminal, it is merely a name for a lifelong set of behaviours. Yours and your child's life may now take a different course than you would have expected, but it is just as important and may even be more fascinating and enlightening. Reading books and learning lots about it is good (I wouldn't bother writing one otherwise), but don't think that they have somehow changed because they have a name for their behaviours. Your kid is still your kid regardless of their label. (Jackson, 2006, p. 27 & 29)

Asperger considered that the characteristics could be identified in some children as young as two or three years, although for other children, the characteristics only became conspicuous some years later. He also noticed that some of the parents, especially the fathers of such children, appeared to share some of the personality characteristics of their child. He

wrote that the condition was probably due to genetic or neurological, rather than psychological or environmental factors. He conceptualized the disorder as a life-long and stable personality type, and did not observe disintegration and fragmentation that occurs in schizophrenia. He also noted that some of the children had specific talents that could lead to successful employment and could develop life-long relationships (Attwood, 2007).

Robison's (2007) symptoms were visible as early as four, but that was approximately three decades before anyone in the United States had ever heard of AS. His childhood experiences were not nearly as positive as Hall or Jackson. When Robison was young, autism was not thought of as a "spectrum" and those diagnosed with it were those that today would be termed "far onto the spectrum."

In the first sixteen years of my life, my parents took me to at least a dozen so-called mental health professionals. Not one of them ever came close to figuring out what was wrong with me. In their defense, I will concede that Asperger's did not yet exist as a diagnosis, but autism did, and no one ever mentioned I might have any kind of autistic spectrum disorder. Autism was viewed by many as a much more extreme condition – one where kids never talked and could not take care of themselves. Rather than take a close and sympathetic look at me, it proved easier and less controversial for the professionals to say I was just lazy, or angry, or defiant. But none of those words led to a solution for my problems. (Robison, 2007, p. 90)

Robison learned a great deal through his own life experience. He learned a lot about pretending and a lot about doing what others expected him to do. He left careers and positions at which he was truly gifted and showed genius talent to pursue management roles that were not a natural fit. He didn't pursue other dreams for fear of failure. As a high school drop-out, he was invited to pursue a prestigious college degree. He had learned from age six not to repeat humiliating experiences. He had failed at school once; he would not try again. His genius with sound equipment led him to Lucas Film; he didn't go for fear he would fail. Based on his natural talents and character traits, he would likely have been very successful there. Instead, he tried to pursue a career in management at a national toy company. While he was a genius at designing talking toys, he was a disaster in corporate management. He eventually found himself in his own business fixing things and working with machines: high end automobiles. It was one of his customers that led him to a diagnosis of AS. This customer had been a friend for 10 years and just happened to be a therapist for troubled teens (Robison, 2007).

TR had taken to coming down to visit me at lunchtime every now and then. One day he said, “Therapists learn not to analyze their friends if they want to have friends. But there is a condition in this book that fits you to a T. I’d like you to read this and see what you think.” And he handed me a book: *Asperger’s Syndrome*, by Tony Attwood.

I picked it up. Warily. “What the hell is this?”

I thought, *Ten seconds ago, I was telling him what I had just read about Caterpillar’s newest D10 bulldozers and how they plan to compete with Komatsu in Asia, and now he hands me this?*

Seeing my wariness he quickly continued, “I’m sorry to spring this on you like this. I’ve thought about it a lot. This book describes you exactly. You could be the poster boy for this condition. Your fascination with trains and bulldozers ... it’s in here. The way you talk. The way you look at people, and how hard it is for you to make eye contact. The way you think.”

“So is there a cure?” I asked.

“It’s not a disease,” he explained. “It doesn’t need curing. It’s just how you are.”

Sitting at the table, I began scanning the book. I always read when I am eating alone, though I have learned that it’s rude to do so when eating with other people. But his moment appeared to be an exception. One of the first things I read was this:

¹Diagnostic Criteria for 299.80 Asperger’s Disorder

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

Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

Well, I thought, that certainly describes me. Not looking at people making the wrong expressions, and gesturing when I should be still ... that was me all right, and it wasn’t good. I kept reading.

Failure to develop peer relationships appropriate to developmental level.

That fit me exactly. When I was younger, I had never been able to connect with kids my own age.

¹ The Diagnostic Criteria here is repeated from page 29-30. This time, however, it is a direct quote from Robison (2007) interspersed with his own thoughts as he first discovers AS – and that there are others like him, so many in fact, that there is a name for them.

A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).

Well, sure. If I can't connect with people, how can I be expected to show them stuff? That was me too.

Lack of social or emotional reciprocity.

I've certainly heard that one before.

I immediately realized he was right. It did fit me. Completely. It was like a revelation. I realized that all the psychologists and psychiatrists and mental health workers I had been sent to as a child had completely missed what TR had seen.

As a child, I had been told I was smart but I was lazy. Reading the pages, I realized I wasn't lazy, just different.

I knew that I did not look at people when I talked to them. Hell, I had been beaten up and criticized for that all through my childhood. But until I read that book I had never realized my behavior was unusual. I had never understood why people treated me the way they did. It had always seemed so mean, so unfair. It had never occurred to me that other people might find what I did (or did not do) naturally disconcerting. The answer to "Why won't you look me in the eye, young man?" was right there in the book.

The realization was staggering. *There are other people like me. So many, in fact, that they have a name for us.*

I kept reading, willing my eyes to pick up the pace. My head spun.

I had spent most of my life listening to people tell me how I was arrogant, aloof, or unfriendly. Now I read that people with Asperger's *display inappropriate facial expressions*. Well, I certainly knew about that. When I was a child, I was told my aunt had died, and I grinned even though I was sad. And I got smacked.

Just reading those pages was a tremendous relief. All my life, I had felt like I didn't fit in. I had always felt like a fraud or, even worse, a sociopath waiting to be found out. But the book told a very different story. I was not a heartless killer waiting to harvest my first victim. I was normal, for what I am.

How could all those so-called professionals have missed that? How could they have been so completely wrong?

To be fair, Asperger's syndrome was not recognized as a distinct condition in the *Diagnostic and Statistical Manual of Mental Disorders*, the bible of mental health professionals, until fairly recently, when I was in my thirties. The upshot was that I spent many years adapting to a condition I didn't know I had. Learning about Asperger's was truly a life-transforming experience.

One of the most surprising things I learned was that Asperger's is an *autistic spectrum disorder*. That is, it's a *form of autism*. ...

If my parents had known what caused me to be the way I was, and acted on that knowledge, life might have turned out very differently for me. My life has been filled with lost chances because I didn't fit in. (Robison, 2007, pp. 235-238)

Causes

There are many hypotheses regarding the causes of autism. At the time of this publication, there is no known specific cause, but there are some potential contributing factors.

NEUROLOGICAL CAUSES

Scientists continue to debate the root causes of AS, with possible culprits including chemical dysfunctions, lesions or structural abnormalities in the brain (Grandin & Barron, 2005). Brain researchers have discovered that autism characteristics manifest when the neuronal connections that link up the many different parts of the brain fail to make the proper connections. The frontal cortex is the most affected area and the back part of the brain, where memories are stored is usually more normal. They have also found that the brain areas that process emotional signals from the eyes are abnormal (Welchew et al., 2005). Klin and others have been doing studies for years on eye tracking and differences in the focus of eye movements between neurotypicals and those on the autistic spectrum. Variability in the parts of the brain that are wired differently properly would explain why behaviors and feelings can be so different among people on the autism spectrum (Allday, 2011; Bertone, Mottron, Jelenic, & Faubert, 2005; Cutler, 2004; Gidley Larson, Bastian, Donchin, Shadmehr, & Moftofsky, 2008; Grandin & Barron, 2005; Klin et al., 2002; Pelphrey, Morris, & McCarthy, 2005; Pierce, Haist, Sedaghat, & Courchesne, 2004).

Brain imaging studies of neurotypicals can identify structures and systems that operate together to form the 'social brain,' then compare these structures with those from people with AS. Research studies that have used brain imaging technology and neuropsychological tests have confirmed that AS is associated with a dysfunction of the 'social brain' which comprises components of the frontal and temporal regions of the cortex (Attwood, 2007). There is also evidence of dysfunction of the amygdala, the basal ganglia and cerebellum (Frith, 2004; Gowen & Miall, 2005; Kleinhans et al., 2008; Toal, Murphy, &

Murphy, 2005). Research suggests weak connectivity between these areas of the brain and there is also evidence of an abnormality of the dopamine system. The psychological profiles of abilities in social reasoning, empathy, resistance to change, communication, recognition of irony and cognition align with neurological brain research and the characteristics shown in those with AS correlate brain wiring differences with brain function (Bird et al., 2010; Gomot, Belmonte, Bullmore, Bernard, & Baron-Cohen, 2008; Wang, Lee, Sigman, & Dapretto, 2006).

There are differences in the use of pronouns, development and use of language between neurotypicals and those on the autistic spectrum depending on interaction with other children, adults or videos (Mizuno et al., 2011; Watson, Roberts, Baranek, Mandulak, & Dalton, 2011). Pragmatic language problems have also been shown to be problematic in both high-level inferential processes and the most basic aspects of pragmatic language processing. There are significant differences in the clusters of brain activities between ASD groups and neurotypicals in fMRI studies (Tesink et al., 2009).

Recent brain studies have discovered differences between those on the autistic spectrum and neurotypicals with mirror neuron systems (Ramachandran, 2011; Robison, 2011). Mirror neuron systems are specialized brain cell pathways that “act out” what we see in other people (Robison, 2011, p. 82). Scientists believe that mirror neuron systems form the foundation for human empathy. Simply put, when one person sees another person smile or frown, mirror neurons cause the response of smiling or frowning in return. Seeing the smile or frown elicits a corresponding feeling – and physical response.

Those with autism or AS, tend to have a weaker response to visual stimuli than neurotypicals (Ramachandran, 2011; Robison, 2011). Researchers are finding that this weaker response shows itself in many different ways, and sometimes at very young ages. John Elder Robison’s (2011) grandmother would pick him up as a toddler and make faces at him. Like most adults, his grandmother anticipated John Elder to giggle and make faces back at her in response. Instead, he stared back at her, puzzled. When she’d had enough, she’d set him back down and say “Why won’t you smile at me? You’re just a mean little boy!” (Robison, 2011, p. 79) John Elder never got the messages from her funny faces, but he got the message that she didn’t like him very much. As he got older, he could easily interpret another child crying with a bloody knee, but still didn’t know how to interpret a

hand held out and a big smile. As he stared at people trying to figure out what they wanted, he got responses like “What’s the matter with you?” and “Don’t you care?” This frequent staring led to bullying, name calling and contributed to his dropping out of high school at age 16 after being expelled for scaring his teacher due to staring at her (Robison, 2007; Robison, 2011).

Mirror neurons don’t just respond to sight. They also act out feelings from sounds, smells and other triggers. In autistic brains, the mirror neuron systems work the same ways as in neurotypical brains, but it is like the volume is turned down which causes a weaker response. A big smile on someone’s face might elicit a tiny grin on the face of an AS person in response. It can also mean taking extra time to interpret the clue. It may be the cause of many of the social interaction symptoms of those on the Autistic Spectrum. Years of negative reactions to those symptoms may be the cause of other conditioned responses to human interaction and turning to inanimate objects as a release from chaos. Those with AS and autism have often been found to live in isolation and perceived to demand everything go their way emotionally. Weak mirror neurons may be a root cause of this or be amplifying it. More studies are under way, but what has been found so far, indicates this is an important discovery (Ramachandran, 2011; Robison, 2011).

PARENTING [NON] CAUSES

Scientists, psychologists and psychiatrists all agree that AS is not caused by inadequate parenting or psychological or physical trauma. Some parents think AS is somehow caused by a defect in their character or parenting skills or not providing enough love for their children or even witnessing some traumatic event or a head injury. In fact, well into the 1960’s, mothers were told their children were autistic due to lack of love and emotional coldness from their mothers (Cutler, 2004). Attwood (2007) encourages parents to abandon such feelings of personal guilt. Research studies have clearly shown that AS is due to a dysfunction of specific structures and systems in the brain. AS brains are ‘wired’ differently, not necessarily defectively, and are not caused by what parents did or did not do during the child’s development. Parents can rest assured that it is not due to faulty parenting.

GENETIC LINKS

While AS is not due to parenting and environmental factors, there are many studies that indicate it is linked to genetics. Dr. Asperger originally noticed a ghosting (weaker, but similar character traits and behavior patterns) of the syndrome in parents of the children he saw, and more frequently in fathers than mothers. He proposed then that the condition could be inherited. Subsequent research has confirmed that there are some families with strikingly similar characteristics in family members. Using strict diagnostic criteria for AS, research indicates that for children diagnosed with AS, about 20 percent of their fathers and five percent of their mothers also have AS (Baron-Cohen, 2004; Volkmar, Klin, & Pauls, 1998). More than two-thirds of the children with AS have second- or third-degree relatives with similar patterns of abilities (Cederlund & Gillberg, 2004).

Some aspects of AS can be perceived as positive traits and family members who share the characteristics of AS often share characteristics that contribute towards success in careers such as engineering, accounting and the arts. There is a greater than expected number of engineers among the parents and grandparents of children with AS (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Temple Grandin's own grandfather would almost surely be diagnosed with AS if he were alive today. He was a brilliant and hyper-focused inventor who displayed nearly all the quirks in personality and social relatedness found in the literature today (Cutler, 2004). Throughout the 1930s, 40s, and 50s, he was just considered odd.

BIOLOGICAL CAUSES

Scientists agree that heredity has a casual effect, and this has prompted a worldwide search for the gene or genes that cause it. In the most extensive findings to date, an international consortium of scientists, including researchers from UCLA's Center for Autism Research and Treatment, announced in 2007 that they had located two new genetic links that may predispose children to develop autism. They hope that finding the biological source will lead to better means of diagnosis and maybe even the development of drugs to treat the condition and not just the symptoms (Armony, 2008).

CHEMICAL OR NUTRITIONAL CAUSES OR ENHANCEMENTS

Others hypothesize that sudden onset symptoms of autism that include regressive speech and almost instant decline in any kind of social interaction, may not be completely caused solely by abnormalities in the brain from birth. These symptoms of autism typically come on suddenly somewhere around the age of two and may suddenly accentuate more mild autistic spectrum symptoms. These symptoms may have caused parents to suspect their child as being different, but they typically had no diagnosis of an ASD beforehand. There are many researchers who theorize that these sudden and severe autism symptoms are brought on by allergens in the body from wheat and milk (Armony, 2008) or the yeast poisoning as a by-product from killing gut flora by premature immunizations on those with weak immune systems (McCarthy, 2007). Underlying nutrition-based approaches to treatment are the belief that severe autism symptoms are not caused solely by neurological abnormalities from birth, but are either triggered by or enhanced by biological factors such as allergens, nutrient deficiencies, or immune system dysfunction (Hershel & Kaye, 2003; Ratajczak, 2011; Szatmari, 2003).

Treatments

By introducing dietary changes, in addition to behavioral based therapies, advocates believe that the body can overcome the symptoms of severe sudden onset symptoms of autism and many of the more severe symptoms can even be cured. Since some of these children deemed as “cured” have been found to have mild symptoms of AS or high functioning autism later, it is believed that the biological causes suddenly aggravated an otherwise mild condition and made it unlivable.

Researchers are divided into two factions: Those who hypothesize that brain abnormalities are the only cause of autistic symptoms and those who hypothesize other outside chemicals or nutrients contribute to or cause the ASDs. Studies are limited. Functional MRIs reveal brain wiring abnormalities from birth. Changes in nutrition have been used with phenomenal success in a number of individual case studies – bringing about significant reduction in autistic symptoms. Studies are based on interruption of small intestinal absorption due to bacterial overgrowth. Undigested sugar molecules remain in the

intestine and end up creating an excess of gases, alcohols and acids creating energy for excessive microbial growth. This excessive microbial growth eventually causes an inability to absorb vitamins that build insulating layers in nerve cells, among other necessary functions in the body. They also compete for nutrients the body needs and create waste the body cannot dispose of through the intestinal tract (Gottschall, 1994; Horvath, Papdimitriou, Rabszty, Drachenberg, & Tildon, 1999). Many scientific skeptics are not yet convinced of their validity, particularly since they presuppose a cause of autism that has not been proven. However, for a growing number of families across the U.S., improvement in their children's social and communicative skills is all the proof they need (Armony, 2008; Bortfeld, 2010). "We'd be nowhere without the alternative treatments," says TACA's Estreep, who credits a GACF diet for enabling her 10-year-old son to engage in reciprocal conversation, experience fewer tantrums and maintain eye contact.

Many parents of those with AS and higher functioning autism have found some behavioral changes with nutritional-based interventions, but have not shown the dramatic spikes and radical personality changes that the dramatic onset autism cases have shown. They also tend to develop their symptoms over a period of years and are typically not diagnosed before the age of eight.

Prevalence

All forms of ASDs are becoming more and more prevalent. To review, Chapter 1 states that based on the DSM-IV criteria, 1 in 1200 children have AS and based on the Gillberg criteria between 1 in 280 and 1 in 210 have AS (Attwood, 2007). A 2006 study by the U.S. Centers for Disease Control and Prevention (CDC) found the prevalence of autism to have increased to as many as one in 110 ("How many children", 2010; Hershel & Kaye, 2003; Rice, 2006; Szatmari, 2003).

Future

To prioritize what to do in the future, it is important to look at what has been successful in the past. Many successes in past decades were discovered by trial-and-error, if not by accident, sometimes decades before knowing anything about AS. These discoveries are every bit as important as recent controlled academic studies. The early interventions have

been tested in real life settings and they can be replicated by real people, usually with little or no money or policy changes. Most are based on common sense, consistency, paying attention to trial-and-error and making adjustments based on individual need.

Temple Grandin is likely the most well documented person of such a real-life test. Temple was too young to recall the tantrum episodes where she tore the wallpaper off her bedroom walls, smeared feces on the walls and furniture and shredded her mattress into tiny bits with her fingers, but through the intuition, persistence and continual acknowledgment and tracking of progress by her mother (Cutler, 2004), what she does recall is the paragraph that follows:

Mother never viewed my autism as excusing me from the expectation that I would learn to function within the social structure. Even at age six, I was expected to eat dinner with the family, to behave properly, and to respect the family rules, such as never messing up the living room. Being polite, saying “please” and “thank you” were expected of all children at that time, and most certainly of children in the Grandin household. It was simply assumed, *without question*, that I would learn these social skills. (Grandin & Barron, 2005, p. 3)

Temple’s mother unknowingly laid the groundwork for much of today’s most effective therapeutic interventions – at a time when society expected and pressured her to institutionalize her child rather than pay attention and document what it took to help her become a fully functioning and contributing member of society.

Teach the Basics

Teach them the basics! Teach them how to relate to others with shared interests and common courtesy. Expose them to a variety of experiences and be cognizant of their sensory limits. Relate to them with logic and don’t burden them with neurotypical need to tie emotions to every activity. Explain EVERYTHING clearly and unemotionally.

The environment I grew up in was also a natural setting for social interaction and for friendships to form. Absent were hours of solitary activities such as watching television and DVD movies, or playing computer and video games, and this was actually a very positive thing for a developing autistic child. Time was spent making things, building projects like kites or model airplanes, in lots of outdoor activities, and in playing board games or cards. The activities taught me turn-taking. ... These type of activities were naturally reinforcing, they were self-esteem building, and they provided opportunities for practicing all sorts of skills, from language to sensory regulation to behavior control.

While some activities I did by myself, in most cases my days were filled with shared activities ... required me to learn to play with another child. And because Mother drilled into me manners and social etiquette, I developed good play skills at a very early age, like turn-taking and being fair and doing what others wanted to do. (Grandin & Barron, 2005, pp. 4-5)

CONSISTENCY

The more consistency that can be added to the child's environments, the easier it is for the child with AS to adapt to different environments. Temple Grandin had an easier time moving from house to house in her neighborhood due to the consistency of social expectations and discipline of the parents.

One of our neighbors had a really cool erector set, another had a pool table – these were activities I enjoyed and I'd often be over there playing with the kids in those families. Socializing was an everyday occurrence and having appropriate social skills was expected. If I acted inappropriately at a neighbor's house, the mom would simply correct my behavior – no big deal – just like my mother did. (Grandin & Barron, 2005, p. 5)

ENGAGE THE CHILD'S NATURAL INCLINATIONS

It is critical to find activities that capture the child's attention and natural inclinations. This will keep them engaged and likely develop the child's natural strengths and talents.

I loved building things right from the start; it was a natural outlet for my visual way of thinking. I wasn't interested in "little girl" activities like playing with dolls (hated them, hated them). I wanted to go out and build tree houses, and construct things that flew, like planes and kites. (Grandin & Barron, 2005, p. 6)

EMOTIONAL RELATEDNESS

Some aspects of autism – especially those that are part of the physical make-up of the brain may never change. Admitting that a child may never develop the emotional relatedness of a neurotypical person feels more like failure than acknowledging that it is simply "another way of being" (Grandin & Barron, 2005, p. 45).

Just recently a teacher was discussing her frustration with not being able to reach one of her AS students and made a comment, "He doesn't seem very emotionally related to me." My response was that he may not be – and may never be – and if she was trying to reach him academically through purely emotional ways, she might never "reach" him at all. I suggested she use his interests in science or some aspect of math or history as a way to relate to him instead. (Grandin & Barron, 2005, p. 45)

DEVELOP TALENTS

Always look at the value of what the child can accomplish and is interested in. Since the early 2000s, more and more emphasis has been placed on social skills, without an equal visionary path to developing talents. Developing talents is essential for the child to successfully transition beyond high school and into adulthood. Parents who are more social people themselves have the hardest time understanding their AS child. Mothers who are engineers or computer programmers themselves seem to deal best with them. Social skills are critical in a neurotypical world, however, parents putting all their effort into emotional relatedness is not always the best investment of time and effort and can cause more frustration than emotional connection.

I've had parents say to me, "I don't think my child actually loves me." These same parents seem to overlook the fact that their child excels in an area, or is making straight As, and could have a very good future ahead of him if his interests are channeled in the right direction. However, the parents put all their attention into trying to develop emotional relatedness in their resulting in a vicious cycle of effort and failure for them both. I think some of these really smart AS kids lack the capacity to ever "measure up" to the level of social connection their parents want from them. Until parents are willing to see their child as he is – not how they wish he would be – and build from there, the child loses out. (Grandin & Barron, 2005, p. 45)

PREPARE FOR ADULTHOOD

Rather than trapping an AS child in a cycle of failure, it is more productive for parents to focus on preparing their AS children for a future that is fulfilling for the child as they develop into adulthood.

I probably sound like a broken record, but it's worth repeating. On the whole, happy AS people are the ones who have satisfying work in their lives that's connected to an area of strong interest. I realize it's difficult for a lot of parents to understand that their child with ASD may derive greater happiness through work or hobbies than through pure emotional bonding, or that marriage or a family may not be at the top of his list of priorities. It's still happiness, nonetheless. (Grandin & Barron, 2005, p. 46)

Temple Grandin (Grandin & Barron, 2005) tells about speaking at a meeting of state educators. Their book table had multiple books about Asperger's, but not one about how to help students transition out of high school and into college or into a job. Even more ironic is that she was the guest speaker and has written a book specifically on the topic. More

emphasis needs to be spent on in the importance of self-esteem, motivation and critical thinking skills that can lead to a successful career. She suggests that guidance counselors spend more time reading publications like *The Wall Street Journal*, *Forbes* and corporate-business magazines and less time reading *Psychology Today* to help these students be better prepared for the future.

It is my opinion that all children and adults – whether or not they have ASD – should be taught social functioning skills and be expected to learn them and use them. These are the mechanics of interaction, the skills we use in daily social situations in all areas of our lives, from home to school to recreation/community settings. ... They allow us to blend in with people around us, to move through that all-important “first impression” stage of interaction. ... Without these skills, children and adults are immediately, and repeatedly, set apart, and the upward battle to regain acceptance begins. For some, they never catch up; the battle never ends.

Mother clearly taught us that we were responsible for our actions, and that when we acted inappropriately, there were consequences. Home life was structured and the school day was structured, which was better aligned with the autistic way of thinking. ... I think if I were in school today, in a class with thirty kids and all the commotion, I'd need an aide in order to survive. (Grandin & Barron, 2005, p. 48 & 8)

Teach them how to function, but do not expect them to become neurotypical.

Preparation for life is about more than just chatting with friends. Emotional relatedness must be balanced with preparation for independent living.

Emotional relatedness is an equally important part of a child's social development. But we should not make it an end goal in itself, nor should we lose sight of the child's capacity for emotional relatedness. Make sure a child is taught social functioning skills, and start those early in life. Work with the child on his emotional relatedness, but acknowledge that for some, their capacity may be much more limited than we would like it to be, and *let that be acceptable*.

Mother prepared me to live in the world, but she didn't try to make me into a social being just so I could hang out with other teenagers at the lake ... Her eyes were on a bigger prize – giving me the skills and nurturing the talents that would allow me to graduate from school, attend college, find a satisfying job and live independently. (Grandin & Barron, 2005, p. 48)

APPLICATION OF TECHNOLOGY

The convergence of increasing prevalence of ASDs, shrinking budgets and ever-increasing costs for medical care is placing more challenges than ever on treatment of children with AS and autism. It has long been known that many children on the Autistic

Spectrum are drawn to computer games (Jackson, 2002) and many adults on the Autistic Spectrum have found fulfilling careers in all aspects of the computer industry. Educators have been working for decades on computer applications that are engaging and educational. Many parents find the computer games an obsession and problematic when they have to be turned off for other activities.

The invention of relatively inexpensive touch-screen tablet computers – and the widespread development of educational applications to go with them – are completely changing the landscape of engagement with technology as a tool for therapeutic and educational interventions. Wide spread access to touch-screen tablets and effective applications are providing opportunities for individual adaptation, as well as the ability to engage more than one child at a time. They are portable with long battery life so they can be used at home, in the car, waiting for a sibling, practically anywhere. Schools have begun to purchasing them on a trial basis (J. Tellier personal communication, September 13, 2011).

Apple Computers was the first to market with its iPad and the “App Store.”² The App Store exploded and there are many “apps,” as they are called, for individuals on the Autistic Spectrum. Apple’s CEO, Steve Jobs, did not foresee the appeal the Apple touch-screen devices would have on the autism community, but is pleased to hear people are finding them beneficial (Bailey, 2011). Google’s Android platform³ also has many apps that run on Android touch-screen devices. Hewlett-Packard (HP) is sponsoring what it calls a “hackathon” in October 2011 to create a series of touch-screen apps in conjunction with the national advocacy group, Autism Speaks (Hacking Autism LIVE Chat, 2011).

HP’s hackathon is promoting apps for any platform or operating systems the apps are designed for. James Taylor, director of HP’s Innovative Program Office said the apps will be reviewed by a steering committee and those selected will be improved and then released to the public for free. “Although we love our [HP] platforms, what’s important is we get the solutions to families” (Bailey, 2011).

² The App Store is Apple’s online shopping center for applications that run on its touch-screen products. The applications are downloaded directly to the individual device. Some are free and some are purchased.

³ Google offers a similar online shopping center similar to Apple’s App Store for applications that run on the Android platform.

EXPOSURE TO NEW THINGS

Children with ASDs need live interaction in order for social skills to become “hard-wired” in their brains. They learn by *doing*, through direct experience, much more than they learn by watching and listening. These lived experiences help students function in a group without becoming immobilized with fear. Adults also need to be aware of putting emotional filters into the teaching. Superfluous information and emotional drama often confuse and frustrate children with ASDs. Keeping the explanations pure and simple helps avoid over-stimulation and makes them easier to understand. Help the child see the world through the logical less-emotion-driven perspective of their ASD mind (Grandin & Barron, 2005).

I didn't start out as a high-functioning child. New situations scared me ... But my mother pushed me into new situations; she had a good sense of how hard she should push me, and she'd make me do things that were uncomfortable. She'd send me on an errand to the lumberyard by myself. She also made me go visit Aunt Ann's ranch even though I was scared to go. After I got there, I loved it. I learned about taking risks, making mistakes, my own capabilities. These were all valuable skills as I was growing up. Even though they caused anxiety, I learned that sometimes I had to do new things that made me scared. (Grandin & Barron, 2005, p. 51)

KEEP EXPECTATIONS HIGH

One of the dangers of a culture riddled with “disabilities” is setting expectations too low. Most AS people are more gifted than disabled. They have high intelligence and need to be challenged in their areas of interest. Make allowances for sensory overload, but patiently and firmly work with them to hold the bar high in other areas.

Adults too quickly make allowances for people with ASD and let inappropriate behaviors slide. They require less from them, probably because they believe they are capable of less. ...

Low expectations are dangerous for people with ASD. Without raising the bar higher and higher, we arbitrarily cap their potential and rob ourselves of the chance to learn what they are actually capable of learning and doing. ... We need to give them the services they need, but within an environment of high expectations and a real belief in their capacities to succeed.

“While we each are individuals, our goal is to work in concert with the rest of the people around us” (Grandin & Barron, 2005, pp.51-54).

WORKING TOGETHER TO MAGNIFY GIFTS AND PREPARE FOR CAREERS

Much of the research regarding AS and autism is focused on young children and adolescents. The evidence is clear that early intervention produces phenomenal results, but as those with AS grow into adulthood, or those adults discover they have AS, they are faced with the challenge of not only fitting in at school and social settings, but applying their talents and natural inclinations to earn a living (Evans & Swogger, 2011; Simone, 2010). This transition to adulthood can be extremely daunting and leaves many unemployed and demoralized. Moshe and Brenda Weitzberg faced this situation when their well educated son with AS was fired from his job bagging groceries (Johnson, 2011).

The Weitzbergs followed the model of a successful Danish company called Specialisterne, or “the Specialists.” Specialisterne employs software testers with autism. Its satisfied clients include Oracle and Microsoft. After the Weitzbergs’ son, Oran, was fired from his grocery bagging job, they started looking into ways they could employ Oran’s skills. They found other companies in Belgium, Japan and Israel are also hiring or training adults with autism as software testers.

Moshe developed a month-long training program and tested it. They named it Aspiritech, a combination of Asperger’s, spirit and technology. Their first client took a chance on them to test an iPhone app and they exceeded his expectations. They are a non-profit and in 2010 received 40% of their revenue from clients. They average finding 50% more bugs when testing than the average neurotypical software testers. They work for \$12 to \$15 per hour. This return on investment has enticed many clients to overlook some of the oddities of these young employees like one tester who hates to drive, another who is bothered by bright lights and vacuum cleaners and one who strongly dislikes the feel of carpet. They harness intense focus, have comfort with repetition, memory for detail and are highly skilled with computers.

The Weitzbergs are not just placing these young adults in their first job through Aspiritech. They are preparing them to build their tolerance for external stimulation, teamwork, improved job skills and to learn what kind of behavior is expected on the job. They want the young adults to leave Aspiritech with a full resume and social skills to put their resumes to good use (Autism Hangout, 2010b; Johnson, 2011). With dedicated

individuals like the Weitzbergs and more organizations like Aspiritech, the future indeed looks bright for young people with AS.

WHAT DOES THE LITERATURE TELL US?

Beginning with Asperger himself, many of the great discoveries regarding AS have come through attentive observation and experimentation in a lived experience. The AS community is incredibly fortunate to have many devoted researchers and practitioners who have documented and shared many of these experiences. This has taken years and has shaped understanding of ASDs, treatment, policies, etc.

The researcher wonders, however, how many parents, practitioners, teachers, and those with AS themselves are discovering things on their own that make life better just as Eustacia Cutler did with her daughter, Temple Grandin? These people, living through the AS experience may not have the time, desire, resources or know-how to have their discoveries published in memoirs and peer-reviewed journals, but if they are effective, does that make them any less valuable to those who are struggling with their own challenges living with ASDs? There must be a way to gather this information while it is happening.

RESEARCH QUESTIONS

A review of the literature shows a void in the knowledge not only of volunteers who come in contact with AS individuals, but parents and teachers as well. Budgets are tight and policy changes are difficult and time consuming to implement. The literature also highlights many examples of intuitive or experienced teachers and parents who have made minor accommodations for AS individuals that cost no money and require no policy changes. These accommodations have made amazing changes in behavior and interaction between AS and neurotypical individuals. They have prepared young AS individuals for adulthood. It is clear from past research that AS individuals can be coached and taught to mitigate behavior differences making it easier for them to adapt. Literature also reveals that when teachers and leaders view AS individuals through a gifted lens rather than a deficit lens, they tend to become more creative and accommodating on their own.

Due to this evidence in the literature, the researcher intends to search for examples from ordinary lives not documented in published, peer-reviewed academic works. The true

test is to find out what works from those who have lived it – and then to share it with others who are living it.

What can we find out from the lived experience of those who lived it to help the rest who are still living through it?

In other words: What can be gained through the lived experience of those living with Asperger's Syndrome that can be shared with parents, teachers and volunteer leaders to benefit others living with Asperger's Syndrome? This leads to the following research questions:

- 1) What are the interventions that had a positive impact on youth with Asperger's Syndrome?
- 2) What are the behavior patterns that had a positive impact on youth with Asperger's Syndrome?
- 3) What interventions were used or not used that had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic, extra-curricular environments and adult life?

CHAPTER 3

ISSUES PRESENTED AND STUDY METHODS

It was necessary to consider why this study was useful and how best to conduct it.

PURPOSE OF THE STUDY

The overall purpose of this study is to survey the personal experiences of individuals with Asperger's Syndrome (AS) analyze and combine them to come up with a shared lived experience. It is the researcher's belief that an examination of the shared lived experiences of people with AS can provide information pertinent to treatment, intervention, and assistance across a broad range of the AS population, and yet still be meaningful to individuals with AS in daily life – and be particularly helpful in educational and extra-curricular settings.

Previous research studies have shown that individuals with AS can learn to interpret social cues, practice behavior techniques, control sensory reactions, and can acquire and practice skills necessary to adapt more easily to everyday life in a neurotypical world without impairing their particular talents and the often intense focus that comes with AS. With diligent coaching and tenacity, people with AS have prepared for successful and fulfilling careers and have adapted to independent living as adults.

Research also shows that no matter how much effort is exerted or skills are acquired (or how “normal” they appear) the AS person will never become neurotypical. They will still view the world through the lens of the autism spectrum. Those teaching, volunteering, or working with an AS individual must consider the behavioral propensities and natural inclinations of the AS person in both their characteristics and individual personality traits when guiding them in schooling, career preparation, life skills, social interactions and other responsibilities.

Nearly all of the well-known researchers who have written about autism and Asperger's Syndrome were parents of a child on the autistic spectrum: Attwood (2007), Kirby (Bashe & Kirby, 2005), Bashe (Bashe & Kirby, 2005) and Kaufman (1994) are

prominent examples. Like many other parents, each of these authors started out searching for information to help their own family. Each one now has a story that has been well refined and fine-tuned due to years of speaking, writing and re-writing. Each parent's story helps us learn more about the varying world of the autistic spectrum: how to deal with the meltdowns, social idiosyncrasies, failures in the school system, how to harness the child's intense powers of concentration, and how to best use their often obsessive gifts that frequently propel an AS child to obtain a doctoral-level knowledge of a certain subject by the time they are in middle school. How many more stories are out there? Where can ordinary parents share their stories? Where can the AS individuals share their own stories? Where can the world gather and learn from these shared stories and life experiences? This study is a step in that direction.

The goal of the study is to identify common interventions, including technology interventions or patterns of behavior used by teachers, parents, or other adult leaders that assisted AS youth to adapt to neurotypical environments at home, school, and other social settings. It is also assumed that the study will reveal deficits in leadership and preparation that might have had a more positive impact if the understanding of AS by these leader had been more current and complete. It was also assumed that the study may reveal some consistency in the symptoms addressed by the interventions and patterns of behavior, but that was not known in advance.

RESEARCH QUESTIONS

- 1) What are the interventions that had a positive impact on youth with Asperger's Syndrome?
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- 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic, extra-curricular environments and adult life?

Choice of Study Methods

The researcher believes that the analysis of the combined lived experience of those with AS will reveal the interventions that had a positive or negative impact, and areas void of interventions. What actually made their lives better, and what could have made their lives better?

There are a number of thorough biographies of AS individuals of varying ages and life experience. Each biography tells a compelling story, in some ways different from the others, suggesting there would be value in gathering more of these “lived experiences” from lesser-known “Aspies” and combining them to look for the commonalities in both behavior patterns and successful interventions. This study will draw on the published biographies and accounts of AS individuals of varying ages and life experience.

At the outset of this study, the researcher considered the potential research methods available. A case study was a possible method, but would limit the number of subjects and require a great deal of pre-planned structure. An ethnography would also work, but only if the entire AS population to study were all gathered in one location, which is not normally the case. Most schools, neighborhoods, or extra-curricular organizations have only a few AS youth at a time or sometimes none at all and the numbers shift over time. Therefore, neither a case study nor an ethnography are the appropriate method to extract the personal experiences of individuals with AS and combine them into a shared lived experience. For that reason, the researcher chose to use a phenomenological approach in this study.

Phenomenology Research Methods

The phenomenological approach is primarily an attempt to understand empirical matters from the perspective of those being studied. Bruyn (cited in Creswell, 1998) stated that phenomenology serves as the rationale behind efforts to understand individuals and to see life as the individuals see it. In order to achieve the purpose of this study, the researcher must also become an inquirer and a storyteller. Phenomenological research is one of the most open-ended methodologies for documenting the truth of the human experience (Guba, & Lincoln, 2005) primarily due to the evolving structure of the interview data and use of the subjects’ exact words in the findings.

“Valle and King (1978) stated that phenomenologically-oriented psychological research seeks to answer two related questions: what is the phenomenon that is experienced and lived, and how does it show itself?” (Creswell, 1998, p. 276) The goal is to discover that which has the same perceived meaning over time in many different situations.

In compiling and analyzing the data, Colaizzi’s *Treatment of Data* model (Creswell, 1998) was primarily followed with some modifications for using static video monologues in place of the live interviews. Colaizzi’s model contains seven steps. Step 7 deals specifically with face-to-face interviews and was eliminated since no live face-to-face interviews could be conducted in this study method. Appendix A outlines steps 1-6 which were followed for this study. (see Appendix A for *Treatment of Data*.) The write-up of the study is patterned after Moustakas’ (1994) design for creating a manuscript with modifications to follow the standard university dissertation template.

Phenomenologists explore the structures of consciousness in human experiences (Creswell, 1998; Polkinghorne, 1989). The phenomenological premise is that the human experience is an inherent structural property and is not constructed by an outside observer (Creswell, 1998).

SAMPLE SIZE

Phenomenology studies are generally done through the process of collecting information primarily through face-to-face interviews. Prior phenomenology studies range from one to 325 participants. A number of researchers have concluded that approximately 10 in-depth participant interviews represent a reasonable study size (Creswell, 1998; Dukes, 1984; Moustakas, 1994; Polkinghorne, 1989; Riemen, 1986).

The internet and social media websites have created an opportunity, not only for sharing entertainment, but for sharing communities of practice and communities of development. One such community is autism and Asperger’s Syndrome. Countless people with AS of all ages and their parents and siblings have shared their stories with the world – and with each other – on video sharing websites such as YouTube. YouTube has offered them a gathering place to share with one another and with neurotypicals. YouTube has become a place of camaraderie. Families have been able to share their stories and many people have shared in response. With the filtering capability based on key words, or tags, it

is very simple to find videos on the topics meaningful to individuals with different needs and different behaviors. Due to the disparate locations and often isolating nature of the symptoms of those with AS, these social media sites allow those with AS and their caretakers to find out they are not alone: There are countless others facing similar challenges.

One of the challenges of this study is taking this raw, unedited data from many individuals and finding common applicable meanings. Studying the lived experience of a group of individuals through such a survey requires a methodology that allows the examination of a broad range of open ended subjective experience.

This study of the lived experiences of AS people seeks to create a discipline within social science that focuses on studying the collective human experience rather than on individual subjects, using methods that examine actual human experiences, rather than in controlled laboratory settings. This involves searching out narratives that expand the range of understanding, voice, and storied variations in human experience.

This phenomenology study gathers lived experiences from 25 individuals from 24 different video clips into one cohesive body following all the principles and academic rigor without losing the truth of their message. In keeping the story both valid and authentic, the writing must be balanced and represent the views of all participants; in this case, the subjects selected in the video monologues (Guba & Lincoln, 2005). This study allows the “voice” of the subjects to be heard. Letting the subjects speak for themselves gives an emotional immediacy to the voices of both the researcher and the subjects and the researcher far beyond their own sites and locales (Guba & Lincoln, 2005). This study gathered 24 videos from social media sites on the internet and combined them to tell a more complete story that answers the five Research Questions presented earlier.

CONDUCT OF THE STUDY

The goal of the study is to answer the Research Questions through the lived experiences captured in video monologues. As stated earlier, a phenomenology is the best type of qualitative research to document the discovery of the lived experience of a group of individuals. Individuals with AS have been studied in a clinical setting and many of their symptoms, behaviors and therapies have been documented clinically or educationally; but studies of their personal lived experiences are rare. Most lived experiences that are captured

are only shared publicly in biographies that have taken years to compile and may have had a publisher's slant on the author's content.

The purpose of this study is to capture the candid unedited experiences of AS individuals and their parents without the filters of publishers, editors or researchers, and then present a compilation of the data using phenomenology as the vehicle to deliver the message.

PARTICIPANTS

The source of research data for this study is videos recorded by AS individuals and parents of AS individuals independent from one another that are already published and accessible in the public domain hosted on public video sharing sites such as YouTube, Flickr, PhotoBucket or SchoolTube. The researcher assumes that the demographic data given by the participants is true and has verified within reason things such as age, gender and family relationships, but since this study is a phenomenological survey the researcher has no way of verifying authenticity or asking subjects for any additional information other than what they chose to state or reveal about themselves in their original posting. Student Participants were selected based on descriptions of their own K-12 or college age experiences no matter what their current age was at the time of recording. Peripheral information such as colloquial speech, accents and visual cues were used to validate demographic data such as age and country of origin. These videos have been used as one-way interviews with the study participants.

Table 1 provides demographic data for the Student Participants.

Table 2 provides demographic data for the Parent Participants.

PERMISSION

Permission from the participants is implied by their overt act of publishing their videos in the public domain. Every reasonable precaution has been taken to maintain anonymity and respect for the individuals involved as though they were personally granting permission for the study. No actual names will be revealed in the data distribution, but demographic data has been captured where possible and applicable to the lived experience related in their videos.

Table 1. Demographics of Student Participants

Student Participants				
Age Range*	Number in Each Age Range	Number of Males in Each Age Range	Number of Females in Each Age Range	Country of Origin
14 – 18	2	2	0	US
19 – 23	5	3	2	Australia / Canada / UK /US
24 – 30	4	4	0	UK
30 – 40	0	0	0	None
40 +	2	1	1	Canada
Total	13	10	3	1 = Australia 2 = Canada 2 = UK 8 = US

*Current age range of participant reporting on their school age experience.

Table 2. Demographics of Parent Participants

Parent Participants*					
Age Range of Parent Participants' Children	Number in Each Age Range	Number of Male Children in Each Age Range	Number of Female Children in Each Age Range	Number of Mothers Reporting for Each Age Range	Number of Fathers Reporting for Each Age Range
< 10	3	3		3	
10 – 14	3	2	1	2	1
15 – 18	7	3	4	3	4
19 +	1	1			1
Total	14	9	5	8	6**

*All Participant Parents were from the US.
 **One father had three children on the autism spectrum. This accounts for 12 Parent Participants representing 14 children.

COLLECTING THE DATA

In lieu of in-depth personal interviews, the researcher selected video monologues from 25 participants. The respected researchers in the field suggest conducting approximately 10 in-depth interviews for a phenomenology study (Creswell, 1998; Dukes, 1984; Moustakas, 1994; Polkinghorne, 1989; Riemen, 1986). In-depth interviews are referenced as approximately two-hours in length with an opportunity to ask the subject questions. Since the researcher was not be able to control the length or the depth of the video monologues, additional participant videos were added to create additional depth and to discover commonality in interventions or behavior trends of teachers, parents and adult leaders as well as emotional responses of the lived experiences of those with Asperger's Syndrome themselves. An attempt was made to select a cross-section of individuals with Asperger's Syndrome as a form of triangulation based on age, gender, social experience, school success and family dynamics describing their own life experience and how Asperger's Syndrome has impacted their lives.

DATA SELECTION

In order to answer the Research Questions, a primary selection criteria was interaction with or interventions by parents, teachers or adult leaders. The video monologue selections focused primarily on the impact of the educational environment, teachers, parents, care-givers, or volunteer leaders. The researcher looked for specific interactions or interventions described by the AS person in their own words that had an impact, either positive or negative, on their own lived experience.

Part of the selection criteria was a description of interventions by or about teachers, adult leaders, or parents that made a difference (either positive or negative) in the AS individual's life. A number of videos were selected because they mentioned the involvement of a parent or teacher. These videos covered a broad range of topics and AS symptoms. Ten of the 25 videos were selected because the parents of an Asperger child were describing the interventions. The parent descriptions were selected due to their detailed descriptions of interventions, their broad perspective of developmental progress over time, and their insight into the impact AS has had on the life of their AS child as well as other family members. In the data selection, the researcher was fortunate enough to find one parent/child set. There

were no other parent/child dyads or pairing and all participants were completely independent from one another.

Twenty four of the videos ranged between four and ten minutes in length with the exception of Subject #10 with an 18 minute video. Subjects #1 through #6 were all parents sharing experiences in one video. Subjects #7 and #8 were husband and wife. They each posted one video individually and participated jointly in two other videos that were selected. Two videos were selected for Subjects #13 and #19.

This study does not use documentaries as the data source. Rather, it examines individual videos posted on public websites. These video monologues tend to be more spontaneous, and, because they are largely unedited, the researcher believes that they are more genuine and heartfelt.

METHODS OF ANALYSIS APPLIED

This study analyzed data in the public domain available via the internet and accessed as if it were in a research library. Once selected, the video monologues were transcribed word-for-word. The researcher reviewed the transcriptions to find statements about how individual subjects have experienced life with AS (Creswell, 1998). The text of the transcriptions was then parsed into the topics which are listed in Appendices B and C. The topics were divided into those found in the transcriptions from the AS individuals (*see* Appendix B) and those found in the transcripts of the parents of those with AS (*see* Appendix C) and organized to show commonalities of the individuals selected for the study.

The interventions and patterns of behavior revealed in the video monologues were then compared with current literature. In analyzing the study data, commonalities as shown through the lens of the subjects' lived experience were used to recommend approaches for working with AS youth primarily in educational and extra-curricular settings, and as a resource for future research.

The descriptions of interventions and behavior patterns varied in length and depth. It was discovered that the videos from the parents are detailed and lengthy and sometimes cover years of their tenacious effort. The descriptions from the youth or young adults with Asperger's Syndrome often focus on one phrase when discussing their parents' involvement. The youth or young adults with Asperger's Syndrome do, however, provide incredibly

detailed and insightful data describing their own lived experience, struggles, triumphs and how they fit in their world. The AS subjects share numerous coping mechanisms gained through their experience.

Step 4 of Colaizzi's *Treatment of Data* (see Appendix A) directs the researcher to divide the content into organized clusters to formulate aggregate meanings. The study subjects had mostly done this themselves due to the size limitation, titles, and tag/key words associated with YouTube. Most public video hosting websites have a size limitation. YouTube limits non-paid accounts to 10 minutes. This limitation creates a necessity for people posting videos to categorize their thoughts. There tended to be many sub-topics contained in an over-arching theme. Most of the individuals posting videos also used key words as search criteria that were descriptive of the subject matter contained in the video monologue.

LIMITATIONS

There are some known limitations to this study. The researcher's inability to ask questions of the subjects during the interview process is a known limitation. Those individuals with AS who are most likely to post videos on a public website may or may not be representative of most people on the autistic spectrum. Due to the tendency toward social deficits, there is a possibility that many on the autistic spectrum do not have the courage or the communication skills to record and post videos like those selected for this study. Therefore, this study may be looking at a small minority of AS individuals who are more extroverted than the norm. These limitations are a byproduct of the study method and using a phenomenological survey.

The researcher has two children of his own with Asperger's Syndrome. Although he has five years of intensive research in autism and Asperger's Syndrome, this brings about the possibility for bias in both data selection and analysis. Like the well-known researchers on autism mentioned earlier, it also brings about a vested interest and a lived experience from which to base the most applicable selections.

There are no other studies using this data source and exact method of analysis. Therefore, there is room for a different lens of interpretation and analysis.

CHAPTER 4

FINDINGS

In each lived experience, there is a building of strength, an ability to tolerate, compensate, and in many cases, a desire to share that lived experience with others.

INTRODUCTION

There is a desire to share who it was and what it was that helped them through the most challenging times and taught them to adapt, overcome, blend, and navigate on their own – and to help others in similar situations become more independent. For some of these individuals, this desire has motivated them to produce videos of themselves, telling their own stories or stories of their children and share them on YouTube and other publicly accessible websites. This is a rich, and largely untapped source to gather data that is unfiltered, uncensored and filled with the raw emotion with no music, coaching from a production crew or writing staff; just people sharing their own lived experiences.

EMERGING PATTERNS

Patterns emerged early in the data analysis. The sub-categories were captured and analyzed to see what patterns the topics in the sub-categories revealed. The research revealed some unexpected results. Most notably was the pattern of the length and depth of the descriptions of interventions by the individuals with Asperger's Syndrome (AS) themselves compared with descriptions of the same or similar kinds of interventions from parents of those with AS. The chasm between the two was enormous. Because of this, the researcher decided to do a comparison between the descriptions from those with AS themselves (*Student Data*, see Appendix B) and the parents of those with AS (*Parent Data*, see Appendix C). The term “student data” applies to Subjects of any current age because many of the adults described interventions and experiences in their lives that referred to themselves during their younger years as students. The term “parent data” applies to those

subjects who had children with Asperger's Syndrome, no matter what the current age of their child(ren). One father included in the study had three children on the autistic spectrum.

Although most of the youth with AS do not specify interventions, and some have limited knowledge of the interventions used on their behalf, their video monologues do provide answers to the Research Questions. For these reasons, the data provided the results the researcher sought to obtain, even though in a slightly unanticipated form. Most of the youth with AS did acknowledge consequences to their own actions and efforts.

Noting the differences in the shared experiences between those with AS and the parents of those with AS, it became apparent that it would be of value to make separate lists of sub-topics discussed by individuals with AS and parents of individuals with AS. Dividing the two lists of sub-topics provided a vivid way of comparing and contrasting the two lenses of observation on several levels. As stated in Chapter 3, the lists are contained in Appendices A and B. There was also overlap between the two lists of topics. A synopsis of the overlap of the topics contained in both the parent data and the student data is captured in Table 3.

Parent and Child Subjects

In the data selection, the researcher was fortunate enough to find one parent/child set. The mother and son both posted videos so one specific example of the same child is described both by himself and his mother. This allowed the researcher to observe the contrast between the child's lived experience and that of the parent. It is important to remember that it is not just the person with Asperger's Syndrome (AS) who has a lived experience surrounding AS. The impact of AS and its symptoms extends to caregivers, as well.

It is the researcher's observation that many of the same kinds of differences between the perspective of the parents and the students also applies to neurotypical youth and their parents as well. Children rarely have a comprehensive awareness of the magnitude of effort required by the adults involved in their lives to meet their needs and ensure their well-being. Neurotypical children are often unaware of the effort parents invest to provide them with opportunities for activities like music lessons, cars to drive, playing on sports teams, and even take things like meal preparation and wound care after an accident for example.

Table 3. Parent and Student Data: Comparison of Overlapping Topics

Topic	Observation
Attention	Mentioned in both, but “Preparing and Reminding,” which is a sub-category of Attention, was only mentioned in the parent data.
ADHD and AS	Mentioned equally on both sides. Literature review tells a lot about this and the data confirms what was found in the literature review.
AS Behaviors	Mentioned numerous times on both sides.
AS Symptoms	Mentioned numerous times on both sides.
Sensory Toleration	Mentioned numerous times on both sides.
Tantrums	Mentioned numerous times on both sides.
Eye Contact	Mentioned occasionally in parent data, but mentioned frequently in student data. One video described it in an emotional way unlike any the researcher found in other places.
Friends	Came up in both, but more often in student data.
Self-Esteem	Mentioned in parent data, but mentioned frequently in personal data.
Social Skills	Nearly equal on both sides.
Diagnosis	Mentioned more frequently in parent data, but also mentioned in student data.
Early Intervention	Strong theme in parent data. Not mentioned directly in student data. However, “Parent Involvement” was one of the specific selection criteria and embedded in the Parent Involvement were many stories of Early Intervention without that exact title.
Therapy	Nearly equal on both sides.
Speech Therapy	Nearly equal on both sides.
Teacher Intervention	Mentioned numerous times on both sides.
Academic Achievement	Not mentioned specifically in the parent data, but implied as an extremely valued outcome. Student data mentioned it several times.
College	Not mentioned specifically in the parent data. However, there was a clear implication that the parents were preparing their children for success in college. Was a huge topic discussed frequently in the student data. This makes sense since most of the subjects appeared to be of college age.
Work / Job Preparation	Extreme focus on both sides.

However, this is usually more challenging for the parent of a child on the autistic spectrum. Due to their tendency toward social deficits and lower executive function, the AS child may be unaware that interventions and strategies, are happening on their behalf.

Presentation and Analysis of the Data

The findings are presented as answers to the Research Questions using comprehensive quotes from the transcribed videos that support that particular Research Question. Each quote is prefaced by an introductory paragraph and most are followed by a summary to provide context and applied meaning. The quotes were analyzed based on the words spoken, the scenarios presented by the Subjects, the contextual clues including the description of the setting, demographic information and information the Subject revealed in other quotes.

STUDENT DATA

There were 13 Student Subjects selected for this study based on a verbal description of an interaction or intervention with a parent, teach or other adult leader. Two videos were selected for Subjects #13 and #19. All the other Student Subjects had one video selected for each of them. These 15 videos ranged between four and ten minutes. Each video was transcribed word-for-word, then parsed into useful segments and analyzed for topics and AS symptoms. The most meaningful clauses were included in the findings.

OVERVIEW

A pattern consistent throughout the data was that most students did not dwell on the interventions in recounting their lived experiences. They had figured out coping mechanisms and had a keen awareness of things that worked – and they wanted very much to share them. Whether to clarify the coping mechanism in their own minds, and/or vent their frustrations with AS and fitting in, almost every case appeared to be coming from a genuine desire to bolster the progress of others and save others from suffering some of the difficulties they experienced. They specified this desire using both direct and implied language. For example, Subjects used phrases like “You just feel like people that should understand you don’t”; “Everybody’s trying to understand you”; “I love working with special needs kids and adults in small groups”; “I want to talk to you about a video on teachers bullying”.

Subject #13, a 25-year-old male, posted 345 videos on YouTube between March 2008 and May 2011. This equates to a video every three to four days – for three years. Most of his videos are approximately seven to eight minute monologues on specific topics that he found challenging throughout his own development, or that others on the spectrum have asked him questions about such as:

- Dating
- Eye Contact
- Stimming: What is it and is it Wrong?
- Relationships
- AS and Anxiety
- Friendship
- Parenting
- The Theory of Mind
- What is Autism? What is Asperger's Syndrome?

He was primarily offering a solution or advice. He also does public speaking. He, like many others in this unofficial “community,” offers his assistance to help others on the spectrum avoid much of the misery he experienced while growing up. This is a theme of assistance ran throughout the videos. The words spoken specifically stated offers of assistance and shared experiences that both stated and implied if others with AS knew what they had been through, they would find life easier to manage, could use their coping mechanisms and know they were not alone in their experiences. Two videos from Subject #13 were selected for this study. Several quotes from his videos are referenced to answer the research questions further in the findings. For example, he used phrases like “I found this to be a very effective thing”; (when learning to make eye contact) “They actually suggested that I get glasses! Yes, now you’re about to learn a major secret of mine. You see ...”; “I had to do it over and over again until finally eventually I did it. I just said ‘I have to do this,’ so I did it”; and specifically encouraged those with AS to stretch themselves and take jobs that may be challenging and attempt to make friends and not use autism or AS as an excuse for bad behavior.

Research Question 1: What Are the Interventions That Had a Positive Impact on Youth with Asperger's Syndrome?

The data indicates that the following interventions that had a positive impact:

- Learning to make eye contact
- Mother's consistent discipline
- Social skills training

See Table 4 at the end of this section for a summary of these interventions and their outcomes.

Alan, Subject #13, provided a very clear example of an intervention by a teacher who did not know he had AS, but clearly understood the value and the challenge of making eye contact.

Another instance, perhaps one of the most vivid instances because I did make eye contact was in the 5th grade. What we had to do was practice making eye contact with someone for a minute straight, someone of the opposite gender. I got paired up with this one girl and I thought she was kind of attractive, and everything like that, but you know, it was just the fact that, first, I didn't want her to think I had feelings for her. I was really nervous about that. Second, I felt like she could really see into me like I said, and the teacher worked on me more than anyone else. Some people had to do two tries; I had to do like 10 tries. She's like "Make eye contact." I'd maybe make eye contact for a little bit, then I'd stop and look away, and you know, at the time, the teacher would try to hold my chin and everything and then let go and then she'd say "You have to do it all on your own Alan" and then I'd stop and all the other kids went and then I went back and did mine all over again. I had to do it over and over again until finally eventually I did it. I just said "I have to do this," so I did it and I hated it! It was so scary, and the girl that I was making eye contact with, she was laughing at me and everything and that even scared me even more and that was the most unpleasant experience. (Alan, Subject #13)

Six years later, with the help of his speech therapist, Alan realized that making eye contact was important. This time he was a more willing participant. This led to some improvement – and eventually to some stronger motivation. Later, dating turned out to be a more important motivation than speech therapy.

I really started thinking about eye contact, probably around the 11th grade when I started to really examine myself and try to improve myself and try to overcome my social awkwardness that is associated with autism and I took a psychology class, an interpersonal communication class that was very effective, but still did not help me too much with eye contact. What really helped me was my speech

therapist. She worked with me on eye contact and I actually got some improvement. I made more eye contact. Even though I was making more eye contact, I did not do it on a consistent basis. Now ya wanna know what really helped me with eye contact? Dating. Because of dating, that has helped me more than anything else. What ended up happening is that I went on one date a few years ago, the only Valentine's date I've had in my life, and the entire dinner I didn't make any eye contact whatsoever and, I was really embarrassed by that 'cause I can make occasional eye contact, but I was really nervous and everything and I didn't make any eye contact and then she made some comment about "Oh, now you make eye contact," or something like that, I don't remember the specifics of the whole thing, but the whole point, is that I realized I wasn't making eye contact. But even then, I didn't improve much.

Then, about a year ago, I went on another date with someone else and then they helped me, actually, they criticized me, but it was effective. They said "What you need to work on Alan is your eye contact. You have everything else going for you, but I felt like you weren't interested because of your lack of eye contact," so at least they helped me out a little bit, and they said, "You need to make eye contact. You need to work on that." They actually suggested that I get glasses! Yes, now you're about to learn a major secret of mine. You see, these glasses here, they're not, um, as you can see, they don't magnify anything. These are pretty much just typical glasses; they're not reading glasses; there's nothing special about them. How they help me is that by wearing these glasses, it's like I have a moving screen in front of me, so it's like I make eye contact, but, there's more distance, like I can look at a movie screen and see the characters' eyes and everything and so it's far more effective. So the eye glasses are perhaps the biggest thing to help me with eye contact because, there's just that extra barrier. So, for individuals with autism, you might want to try using eye glasses to make eye contact. Now if you wear glasses on a regular basis, maybe it's not as effective, I don't know, but I found this to be a very effective thing, as far as eye contact goes. (Alan, Subject #13)

Will, Subject #14, did not say how old he was when he was adopted, but he made it clear that the interventions by his mother were both necessary and effective.

I've overcome a lot of struggles thanks to my mom. When I was little, I was really screwed up. I was a screwed up little kid. I would act out my imagination and, not really paying attention, but then I was adopted by my mom and she knew how to deal with autistic kids and she pretty much, as she raised me, she trained me to be a normal person, just kinda being strict with me at times and causing me to think differently and build some of my own self-discipline, and I pretty much I can function in the world. (Will, Subject #14)

For Will, this self-discipline continues to pay off.

As for personal relationships, ... growing up, I was able to make a few friends, usually other outcasts, which was fine. I got a few friends from high school that I still talk to which I think for me, I'm very fortunate to have, because

for me, they're the people who did not look down on me as, like I was a creep or a weirdo. My friends now are not the ones who avoided me. I can pretty much be polite and I know how to treat other people with respect and come across as a friendly person. (Will, Subject #14)

There are a number of therapeutic social skills training programs available. Collin, Subject #15, gives an honest assessment of his willingness to participate – and the outcome resulting from his participation.

I mentioned a couple of times before how I've gotten social skills training. The question is today: "What is that social skills training like?" What does that look like? Well, there are a bunch of different types of social skills training that I took. Some were a little bit more therapy based; of course ya had individual appointments with therapists to talk about school and stuff and how you could have done them differently.

Sometimes there were group therapy sessions that I would go to. I wasn't crazy too much about those. I met a lot of my friends when I was a kid through those because that's what we had in common to keep us together. Those basically consisted of, close to the things you would do in a one-on-one therapy session, talking about what happened during your day and what went right and what went wrong; how do you fix what went wrong. It also was talking about, how to make friends, how to avoid people that aren't gonna be nice to you when you're a kid, and then there were some of the sessions that were a little bit more blunt. I know when I was in school, sometimes I would go into their little classroom, and I'd be sitting there either one-on-one with another person, and basically, we'd go over flashcards, and different pictures and words to show us different examples of eye contact, different examples of facial expression, because Asperger people, we generally have a lot of trouble reading that, and they would do group things with that too, but I don't know. I could've probably used them, but I was kind of a dick and I decided that I didn't want to embarrass myself that much, so it was really hard to get me to go to the group sessions where they show the flash cards 'cause I was always embarrassed and I think that's true with a lot of Asperger people. I think the only difference is, I was a little bit more vicious about it if I didn't want to do it. Basically what these sessions would do is, there'd be some role playing involved, like we'd talk about somethin' that we liked only while talking about it, we'd talk to the instructor, practicing those skills, and it was very difficult at first trying to keep eye contact 'cause that was one of the big issues for me. I had a lot of trouble learning to keep eye contact. I don't know why. It just had made me nervous for so long. The other thing was, um, ya know, to give a little bit of air time and let other people speak. That took me a while to do, and ya know, when I'm talking about something really passionately, I still have quite a bit of trouble doing that.

Do I think the therapy groups helped me out a lot? I think they did. I think that [on the] the whole social seminars really did help out a lot. I mean, they weren't the only thing that helped. I think a lot of being Asperger's was also

trial-and-error with people, but it definitely helped, because I think if I didn't have those groups and those seminars that I went to, I probably wouldn't know that I was doing anything wrong and I'd probably keep the social skills that I had and if that was the case, I probably wouldn't have a lot of friends now. (Collin, Subject #15)

As noted in Table 4, those interventions that were personally important to the students and captured their interest resulted in the most progress. Alan, Subject #13, for example, made several attempts to improve his eye contact, but once he made the emotional connection to girls and dating and realized his dates were feeling rejected by his lack of eye contact, he applied an additional level of fortitude. He also had the good fortune of a date who cared enough to help him come up with a coping mechanism in the glasses that proved to be an ideal solution.

Table 4. Research Question 1 – Student Data – What are the Interventions that had a Positive Impact on Youth with Asperger's Syndrome?

Subject #	13	13	13	14	15
Subject Demographics	Male 24-30 US	Male 24-30 US	Male 24-30 US	Male 18-23 Canada	Male 18-23 US
Intervention	Mandatory 5 th grade eye contact activity	Self-attempt to overcome social awkwardness including psych & interpersonal communication classes	Dating helped with eye contact; Glasses were new intervention for eye contact	Mother applied strict discipline & held to "normal" standards of behavior	Social Skills Training
Outcome	10 tries; forced himself to finish the task	Progress, but not much eye contact	Glasses created imaginary border & led to improved eye contact	Functions in the world & has friends	Helped him figure out what he was doing wrong; changed behaviors; has friends

Collin, Subject #15, admitted that he had rejected the intervention of social skills training and likely lessened its effectiveness. He also admitted that the value of that intervention has had a life-long positive outcome for him and he owes most of his friendships to it.

All three of these Subjects including Will, Subject #14, indirectly referenced the benefit of the care providers getting to know them as individuals and applying the interventions that were appropriate for them as an individual. This was a big part of the positive impact of the interventions' effectiveness.

Research Question 2: What Are the Behavior Patterns that had a Positive Impact on Youth with Asperger's Syndrome?

The data indicates the following behavior patterns that had a positive impact:

- Family patience and understanding
- Realistic expectations of loved ones
- Volunteer service
- Teacher adaptation to individual students
- Adapt physical surroundings
- Apply non-emotional problem solving

See Table 5 at the end of this section for a summary of these interventions and their outcomes.

When answering this question, James, Subject #16, not only shares the positive behaviors of his family, but the not-so-positive behaviors of his family interacting with him pre-AS diagnosis. James acknowledges the difficulty for family members to understand the person with AS and realizes that it wears them down. Once his family learned about AS and about what to expect from him, they became an incredible support system to him. He is grateful for the shift in his family's understanding and their tolerance. He takes great solace in their new found kindness.

The support somebody with Asperger's Syndrome would get from their families: I thought it was something that I could kinda talk about quite well, actually 'cause I've been on both ends of the scale really as I wasn't diagnosed till I was 20. I didn't have much support or understanding until about a year before then and, since after it's been very different and there's been more support and stuff and it's been great. Us Aspies, we can have some quite, what some people would consider unusual behaviors, like stimming, melt-downs, the way we react to things. It's very difficult, I find, for people to understand that, certainly if there's no clue as to what it is and, um, ya know, my family would get angry with me; they'd get frustrated with me. They wouldn't really know how to respond to me. It would never kind of cross their mind that it was something I couldn't help. It

was just something that was kind of an annoyance to them really and obviously if you feel that your family don't support you, then you kinda feel very very alone and I think certainly don't have self-esteem and confidence. You just feel like the people that should understand you don't, and it can be quite, hard to live with. I mean, you love those people and you do your best to understand them, but everybody's trying to understand you, which to be fair, it's a damn tough thing. It's a really tough thing to try and understand somebody who has Asperger's because we can be quite different; we can display behaviors that some people might find extreme or weird. I personally don't think it's weird, I just think those traits kind of sum up who we are and I would never ever sum up somebody who has Asperger's Syndrome as weird, never in a million years. But my mum was always really good. She would always give me cuddles and stuff and I knew I was always loved; I just wasn't very understood and I just think that bit of understanding that I do have now, that's the difference between being very alone with things and to actually feel that now I know that if I have problems with my Asperger's or things kind of get on top of me too much, I can go to my family and they will understand me, or they'll certainly try to. It's just wonderful to be able to have people, have your family, to kinda go to when you kinda feel lost in a way.

You know, I had a challenging week last week and I needed my family and I needed the support that they gave me and they were just immaculate; they were amazing. I mean they were there for me; they listened to me; they talked to me; they just wanted to help, and just having people who want to help you; having your family there and understanding where you're coming from and understanding the difficulties that you have and to try and want to try and sort of support you with it is just an immense difference from kind of feeling very very alone, I just think if anybody wants to know how to find the support, Aspies they might be kids or friends or what. (James, Subject #16)

Much like James, Hank, Subject #17's relationship with his family changed after his diagnosis with AS. Hank describes a level of self-discipline contrary to that described later by Alan, Subject #13, when answering Research Question 4.

Now that my sons know and my wife knows that I have this syndrome, they're much more forgiving and they're more willing to kind of accommodate me. One thing that I've felt that's always been good is that my wife and my sons have always known that I love them and care for them. That's never been a doubt in their mind. I don't blow up at people. The frustration I feel, I'm somehow able to keep it from going that far. Some of my friends here know people who are autistic and have Asperger's and they get frustrated and they kind of blow up with an angry response. For some reason, that's not part of my profile, and probably because of the family I was raised where I was just strictly forbidden to ever do that, and so I keep that under control. (Hank, Subject #17)

Subject #18, David's experience could be considered an intervention rather than a behavior pattern, but as his video progressed, it became apparent that his discovery of service

– and the instinctive support of that desire to serve was more than an intervention. This discovery has had a far reaching impact on David’s life and was possible because of the behavior patterns shown by the adults who encouraged and enabled him and by his own actions. This extraordinary level of volunteering also reveals a common AS behavior tendency of fixating on one or two interests or behaviors with intense focus, often to the exclusion of things that neurotypicals find important or even necessary.

The most pivotal moment in my life came in high school, when I discovered Ms. Rosevear’s Service Learning Class. The class required two hours of class and three hours of volunteer work each week. But I enjoyed volunteering so much that I put in a few more hours than required; about 1500 hours extra! Teachers took note of this and one teacher helped me pay for two years of college, something my mom could not, and my dad chose not to. During college breaks, I volunteered with people with disabilities. (David, Subject #18)

David has carried this passion for service into adulthood. He has emulated as many character traits as possible from those he admires around him and shares his gratitude for them as part of his lived experience. David now realizes the service rendered by his sister toward him due to his long drawn out behavioral challenges.

Volunteering has taught me that I wouldn’t be a very good mainstream teacher or professor. My voice puts a class to sleep! But, I love working with special needs kids and adults in small groups whether at camp or school. However, our society doesn’t seem to value these jobs enough to provide a living wage. I have the utmost respect for those who choose to teach instead of chasing high salaries like Anthony J. Mullen who received the National Teacher Award in 2009. Thanks also to my many volunteer supervisors over the years. And also my sister, Kathy. She taught me many things, and acted as my interpreter back when few others could understand my ‘language.’ Sadly, with the frequent negative attention I received, she didn’t receive much of the positive attention she needed, which wasn’t fair. This is common within families with special needs kids. My ‘Nana’ spent all 76 years of her life helping others. I miss her very much. My Nana and my mother have by far been the most important teachers in my life.

For now, I volunteer when I’m not working or traveling, and I travel a lot due to my Aspie passion for trains. Other members of my family also do volunteer work, especially one of my grandfathers. I hope to match his volume and quality of volunteer work when I’m older and retired, which is a rather ambitious goal.

Every child and adult is special, not just the ones who grow up to be doctors and lawyers. I think of myself as “differently-abled” rather than disabled. There are certain things in life I may never obtain, and I’m just fine with that. For me, the journey is more important than the destination. If someone is to focus on my weaknesses, such as my not driving, challenges with certain types of

communication, and other 'quirks,' then they're not looking at the big picture, as I have many talents and a positive attitude. "If you want to win competitions, then breed race horses dammit, don't have kids!" said Aamir Khan. If you've never volunteered before, please consider it. (David, Subject #18)

Hank, Subject #17, talked about a teacher who not only displayed her behavior patterns while she was his teacher in the first grade, but throughout his life. This acted as an intervention for him, but he presented it in the context of her behavior patterns and how they benefited many of her students over the years.

This teacher had a profound effect on my life and became a student of who I was and was keenly interested in my development. I only had her for six weeks and I arrived at that new school as a first grader. Uh, I knew I was failing grade one and I was terrified I was going to have to repeat the grade, but for some reason, she took a special interest in me. Thirty years later I found out she did that with all of her students, especially with students that quote "didn't fit the norm." I found out she'd been watching my career from grade one onwards. I had tea with her when I was in my early 40's, and she just told me "you were the mystery student I couldn't figure out, so I decided to follow your path after grade one," but it was because of her I got into the second grade. She had confidence that I was going to make [it] in the second grade, and I think especially since how well I did in second grade, she just decided "I gotta watch this kid from here on in." ... Nobody even knew about Asperger's or autism when I was growing up, it's now people are recognizing it. But in one sense, I think I had the benefit of being treated like a normal kid, ya know, kinda going through that and realizing I had talents other kids didn't have, so I began to focus on that. (Hank, Subject #17)

As an adult with AS, Hank has figured out how to use his AS traits for the good of others and to earn a living for himself. Hank has also discovered an awareness for the pros and cons that his AS traits and insights bring to his organization.

People here at the office laugh that I have the blinds closed and I keep my door closed and I don't care if it's dark because that helps me to focus, and what I realize is I have the capacity to focus that very few other people are able to do and it actually assists me in doing the research, and the fact is, one of the hallmarks of [this business] is we help people through controversial issues in a non-emotional way, but I think my Asperger's really feeds into that. It's easy for me to look at a problem and say "Well, let's just dispense with the emotional aspects of this issue and just look at it logically and rationally," so people here joke that I'm the Dr. Spock of the organization, but there's a real value in being able to cut through the emotions and say "Okay, what's really going on here?" in a rational, logical base and then try to give people an answer; but then I'm tempted to think, "ya know, this is a logical rational answer to this; this should be enough," and not really take into account ... Why doesn't everybody really accept this as a solved problem? [laugh] Well, it's because there's a lot of emotional baggage there, so often I overlook that, and sometimes it hurts people. (Hank, Subject #17)

As noted in Table 5, most of the behavior patterns that had a positive impact on youth with AS involved relationships with other people. These behavior patterns tended to involve creating an emotionally safe environment and building confidence. In the case of David, Subject #18, it did involve setting up a systematic structure to accommodate AS traits and obsessions. Hank, Subject #17, found as an adult, that he needed to control his own behavior patterns in order to be productive and focused at work. Closing the blinds and doors and dimming the lights aided him in obtaining periods of intense focus. Although this seemed odd to his colleagues, it proved quite useful and productive to the organization.

Table 5. Research Question 2 – Student Data – What are the Behavior Patterns that had a Positive Impact on Youth with Asperger’s Syndrome?

Subject #	16	17	18	17	17
Subject Demographics	Male 18-23 UK	Male 40+ Canada	Male 24-30 US	Male 40+ Canada	Male 40+ Canada
Behavior Patterns	Family listened, talked, wanted to help & understood	Wife & sons more willing to accommodate; Hank does not blow up at them or have angry responses	Volunteer service	Teacher keenly interested in & adapted to individual student & showed confidence in his abilities	Closes blinds & doors, dims lights; Applies non-emotional problem solving
Outcome	Felt supported & not alone; Relationship changed after diagnosis	Family knows Hank loves them; he feels supported	Gave life purpose & involvement	Passed 1 st grade; Succeeded in future grades due to increased confidence; Realized he had talents other kids did not	Intense focus; Helps people solve problems without emotional baggage

The common theme throughout each of these behavior patterns is that each was adapted to the needs of the individual. This personalization or modification to fit the individual appeared to be what made the behavior pattern meaningful to the person with AS.

Research Question 3: What interventions were used that had a negative impact on youth with Asperger's Syndrome?

The data indicates the following interventions that had a negative impact on youth with AS:

- Demand eye contact with physical discipline
- Slapping nursery school children
- School staff not noticing loner children wandering on playgrounds (Lack of intervention)
- School staff expressing low expectations of students
- Angry outbursts

See Table 6 at the end of this section for a summary of these interventions and their outcomes.

Alan, Subject #13, recorded an entire video relating to eye contact. Most of the video related to positive interactions and teacher interventions, but he shared one intimate lived experience with his grandmother that answers this research question. This experience reveals that no matter what level of discipline is used, an AS child will never become neurotypical.

I recall when I was very young one time I got into trouble with my grandma when she came to visit, and she told me to look in her eyes and I did my best, ya know, I thought I was making eye contact. I could see her eyes. If I can see their eyes, then in my opinion, it's making eye contact, at least back then it was. I could see her eyes, but I wasn't looking directly into her eyes and I didn't know exactly what she meant, so she kept on smacking me and she's like "Look into my eyes" and I, I tried and she'd smack me again. Ya know, I think she thought I was playing games with her or something, but she smacked me over and over and I really wanted to look into her eyes because I didn't want to be smacked. I mean, that was pretty painful and I was like "But I am looking into your eyes" and she was like "Don't play games. Don't mess around." That was one instance I can recall, where I thought I was looking into people's eyes. I also think that other individuals with autism they think that if they see someone's eyes, that they're making eye contact. That's how I feel, even after that whole punch with my grandma, I think never did make eye contact with her. I did my best, but I think she eventually gave up, or my mom came in or something, but still, after that, I still didn't make eye contact. (Alan, Subject #13)

Like Alan, Andrew, Subject #19, had some life-defining experiences early on. It is clear that even though this experience was nearly 20 years before his diagnosis with AS, his mother was actively involved attempting to place him in an appropriate educational environment matched to his needs and protecting him as best she could.

I did start off at a play school which you call a nursery. I went into play school and I can't remember much about it, but I ended up getting slapped around the face by one of the teachers there. Um, I don't think she could cope with me and it was basically due to my melt-downs or something like that. Anyway, mum was very annoyed and had a go at her and she got banned and we both got banned. [laugh] The first place we got banned from was the play school. (Andrew, Subject #19)

After Andrew and his mother were banned from the play school, they tried a more mainstream route. His autism signs were still not understood by the staff or the other students.

I went to main stream. I went to a Catholic school. That's when things really became apparent. The first day, I decided to let the birdie out of the cage. I think I didn't like it being in captivity. I think it was roughly a similar sort of time that my mum was called down to get me out of the toilets because I wouldn't go out. I think that was when it became apparent that I was different. I also did not make friends easily and I used to walk around the perimeter of the playground and basically was in my own world, so-to-speak, which is very classic autism, very classic and, of course the teachers were oblivious to this really. The kids knew I was different. (Andrew, Subject #19)

Andrew's father was also involved in his education. After two failed attempts in traditional school settings, his father insisted they try a special needs environment. This led to specific bullying incidents mentioned later, but also to several interactions that answer this research question.

Straight into Charles Burns, which was a place for behavioral people. Two schools of thought here: My father felt that I needed to go to the place; my mum was a bit apprehensive. They both discussed it and they both then said "Please observe our son" and they said "Well there's nothing wrong with him and my dad said "Just give it another week" and I think I broke after a few weeks and they said "No, you were right and we were wrong." Charles Burns? Mainly different kinds of special needs – all kinds of different children. The antiquated pin-down regime.

Dr. Byehart at the time was very very good and said "He'll either be a criminal you know, or he'll be a genius." I won't tell you which one worked out. Other things they told my mum, "He'll never ever be able to read; never be able to write; never be able to drive; never have his own place; never have a family of his own; never, never have a girlfriend; never be able to make friends. So, my mum thought I was going to be some vegetable – you know, silly really, and when my mum asked if I was dyslexic because I had a bit of a problem when I was writing stuff, the woman turned around to mum and said "dyslexia, mind you, is just a middle-class name for being called retarded." That's how thick and stupid they were in those days. (Andrew, Subject #19)

Sometimes the person with AS creates their own negative interactions when they haven't been taught and/or coached through constructive social interactions. Will, Subject #14, and his step-father had many angry interactions that may have contributed to his interpretation of other people, negative attitude, and lack of self-discipline.

Growing up I had some serious misunderstands of communications of things that were said. I didn't understand what my parents would say or do and I grew up thinking that everything was about a massive power trip like if someone got mad at me, I thought they were just using my mistake as a means to power trip and assert themselves by getting pissed off at me. I didn't know better at the time and of course, I accepted it as normal. As a kid and as I got older, I got real bitter about it. One of the effects of the huge series of misunderstandings was that I developed a really bad guilty conscience I call it and I pretty much felt guilty about things that weren't that big of a deal even if I accidentally creeped other people out at school or things like that, I'd just feel like a bad person, or if something went wrong, I made a mistake, I always thought I was going to get in so much trouble for this or that, but now I know better and I know that if people get mad at me, it's not so they can power trip. (Will, Subject #14)

As noted in Table 6, in contrast to the interventions that had a positive impact on youth with AS, the interventions that had a negative impact coincided with a complete disregard for treating the child as an individual. In fact, there was a theme of denial that there were any differences in children – or at least that none should be accommodated. It was as if every human being were expected to behave as a robot: exactly the same every time. When the children did not meet the adults' expectations, they were punished rather than understood. Alan, Subject #13's experience being hit by his grandmother demonstrates a common misunderstanding that a person with AS can be disciplined into neurotypical behavior.

Andrew, Subject #19, showed a typical defense mechanism: after being slapped by teachers, transferring to a new school, then feeling intimidated by the other children, he escaped into a safe zone. He hid in the restroom stall and when he did come out, he wandered around the perimeter of the playground where he would not be required to interact with anyone. His teachers made no attempt to get him included in the activities with the other children and did not even acknowledge he was there. When he did interact with staff, they predicted a very dim future for him.

Table 6. Research Question 3 – Student Data – What Interventions were Used that had a Negative Impact on Youth with Asperger’s Syndrome?

Subject #	13	19	19	19	14
Subject Demographics	Male 24-30 US	Male 24-30 US	Male 24-30 US	Male 24-30 US	Male 18-23 Canada
Interventions	Grandmother demanded eye contact: smacked Alan over & over when she didn’t get it	Slapped by teachers at nursery school	Parents removed Andrew from Catholic School	Staff at special ed school proposed low expectation for Andrew’s future	Step-father had constant angry outbursts
Outcome	Never did make “proper” eye contact; Mother had to rescue; Left life-long indelible memory	He & his mother were banned from the nursery school	Andrew hid in school restroom, walked around perimeter of playground; Did not interact with other children	Proved staff wrong, but many years later	Serious mis-understandings & perceived all adults as being on a continuous power trip making him bitter

Will, Subject #14, learned to mistrust and misinterpret most of the adult world because of his exposure to anger in the home.

**Research Question 4:
What Behavior Patterns had a Negative Impact on
Youth with Asperger’s Syndrome that Could Have
Been Changed Based on Current Knowledge?**

The data indicates the following behavior patterns that had a negative impact on youth with AS:

- Unsafe reactions to frustrations with students
- Accuse students of being rude rather than shy
- School leadership verbalizing frustration with non-conforming students
- Bullies chasing students around
- Teachers ridiculing in front of other students
- Use autism diagnosis as an excuse to be rude

- Use autism diagnosis as an excuse to be lazy
- Parents use autism diagnosis to needlessly lower expectations
- No perceiving emotional needs of others
- Propagating social stigmas
- Take easy classes [below capabilities]
- Judge function by a person's looks

See Tables 7 and 8 at the end of this section for a summary of these interventions and their outcomes.

In comparing the topics mentioned in the student data vs. the parent data, there were some notable differences described in Table 3. The most glaring of these differences not listed in Table 3 due to the lack of cross-over, was the mention of bullying. Bullying was a topic of conversation nine separate and distinct times in the transcriptions of personal data, (topics noted in Appendix B) but was not mentioned a single time in the parent data. Only one video was selected because of the bullying topic due to its interaction with and bullying by teachers. What makes this more intriguing is that seven of the nine times the topic of bullying was mentioned, the bullying was done by teachers or school staff, not by peers. (Note: one of the goals of the research was to find interventions and behavior patterns used by parents, teachers and volunteer leaders.)

Andrew, Subject #19, witnessed and experienced the following somewhere between age six and eight.

I witnessed was this lad being thrown in the air and his head hit the concrete, that was, that was the worst thing I ever saw! I was also locked in a vaulting box. I can't remember if it was by a teacher, but it was by force. I was also pinned down a number of times in the pin-down room and I was also told by a tutor, well, a care worker, basically, that if I'd have been her child, she'd have aborted me. (Andrew, Subject #19)

Annalisa, Subject, #20, was in her 20's when recording two full 10-minute videos describing multiple experiences all related to bullying by teachers. The following is just a brief excerpt of the impact this experience has had on her life:

I want to talk to you about a video on teachers bullying. You may be thinking, "What's she talking about? Teachers: they don't bully people. Why would she even say that? Bullying's what kids do." But the thing is: It's not only kids who bully. A lot of teachers pick on kids 'cause they're different or they just like to embarrass people; I mean you can't honestly say that all teachers are nice? I've

had teachers stand me up in front of the class and say “You’re not shy, you’re just a rude, selfish little girl” for doing something really minor, I mean, it’s a form of bullying. I’ve had three or four teachers bully me and put me down and I think that’s pretty bad. No one even knew that I had Asperger’s back in primary school, they just treated me like a freak because I was different, or that I wasn’t worth acknowledging and stuff like that. (Annalissa, Subject #20)

Simon, Subject #21, is lucky to have the fortitude to press on on his own, but has clearly given up on the school system to help him.

I’m 14 and I’m currently dealing with a grueling high school education; I’m diagnosed with Asperger’s. ... at this point, I’ve just given up. I’ve stopped looking for better schools. The principal, he said he wanted to knock me flat – and I would grow again from that – meaning I would act differently, and, you know, be neutralized and I’ll have homogeneous rather than heterogeneous thought. Um, but that’s not gonna happen. I just realized that any high school I go to, I’m going to be miserable and I’ve just stopped caring. I educate myself at home, but at this point, since I look forward to college, where at least hopefully there’ll be heterogeneous thought, I am going to continue doing my work. It’s incredibly difficult for someone with Asperger’s in school. (Simon, Subject #21)

There are times when the social setting itself creates a negative situation that could possibly be different with the right training and “setting the stage” for everyone involved. Perhaps in Subject #19, Andrew’s case, maturity along with the training is all it would take to make the experience different. This experience is clearly about the bullying behavior patterns of the children and answers Research Question 4, but it ends with a specific intervention: his transfer to another school. For this reason, it also answers to Research Question 3 regarding interventions that had a negative impact on youth with AS. Sometimes those with AS do stand up for themselves like Andrew did, but the consequences can be misplaced like when Andrew was punished for defending himself. This may be partly due to the communication deficits of the person with AS or simply the laziness or frustration on the part of the school administrators. The researcher has no way of knowing the school’s perspective of this lived experience, but it certainly left a vivid impression on Andrew, Subject #19, some 20 years later.

I was about 5-years-old at this time and no one really saw anything different. I didn’t mix with the other kids, but there were a lot of shy kids as well. So, there was nothing different and there was this stupid lad called Jonathan; he used to bully me in sort of like [hands smack together with fist] hit me in the arm all the time. One day, he was chasing me around the desk and I decided I didn’t really want to be chased around the desk anymore. I’d had enough, so I stopped and I punched him one and straight in his nose [laugh] and I didn’t really know what

I'd done, but I got into trouble for it. I finally had to go to the special school.
(Andrew, Subject #19)

Sometimes the bullying is subtle and even shrouded in humor, as related by Gary,
Subject #22.

I had my history teacher at school, [laugh] I could never pass one of her tests, and one year, I asked her if she would put my test face down 'cause I knew I didn't do good, even though I would study a lot, and she said "YOU SHOULD PUT YOUR FACE DOWN FOR WHAT YOU GOT ON THIS TEST." (Gary, Subject #22)

Once in a while the bully does get stunned by the reaction of their intended victim.

I had a college lady say once to me, um, she could tell that I smiled at something I was thinking during a class and she looks at me and she was such a pain, and said, "I see you smiling over there. Is there something you want to share with us?" and I say "No" [shortly] "NYOOO?" [teacher] "No. There's nothing I want to share with you right now. No." and she just kind of paused, stunned, and then continued her lecture. I knew she was picking on me. (Gary, Subject #22)

Besides bullying, other behavior patterns include perceived rude behavior and tantrums. Alan, Subject #13, recorded an entire video about people on the autistic spectrum using their disorders as an excuse to be rude themselves and how knowing behavior tendencies typically associated with ASDs can be limiting, create apathy and lack self-discipline for those on the autistic spectrum.

I have noticed that a lot of people on the spectrum of autism, mild functioning autism, Asperger's Syndrome, they do use Asperger's Syndrome or autism as an excuse for who they are and their actions, even some of their bad behaviors. What I mean by bad behaviors is something that would be like yelling, screaming. Um, don't get me wrong, I've been through the whole tantrum phase and all that myself, so you know, I'm not pointing fingers at anyone right here. As a matter of fact, I'm gonna use myself as an example because in the past, I'd put limitations on myself. I would say "Oh, I can't do that because, um, having autism" and ya know, I wouldn't even be aware of what I was saying, I'd be talking to people and I'd be like, "I'm this way because of autism;" "you know I can't make friends this way because of autism." (Alan, Subject #13)

In other areas, Alan is highly complementary of his mother's relentless efforts on his behalf, but here Alan shares a perspective that also limited the expectations his mother had for him, and how those limited expectations negatively affected his self-confidence. Because of his advice, this could also have answered Research Question 5 regarding those interventions and behavior patterns that had application across a broad range of youth with AS.

A lot of this I realized came as a result of my mom more than anything, telling me that I couldn't do certain things because of my autism and also her constant repeating what my autism was, what my limitations were, and how that defined me. And so, parents: I'm gonna go say this again, ya know, when you tell your child this, they're gonna start repeating that into their head and they start telling other people that. If you say to your kid, "Oh, your bad behavior, hitting other people and stuff, that's because of your autism. You can't help it. You know, there's nothing you can do to stop it." When you constantly tell them that, they're not going to do anything to make that change. As a matter of fact, they're going to start saying to other people "Well why do you hit people?" "Well, I have autism, I have Asperger's Syndrome," whatever and you know what? That's what they're going to tell the psychologist or whatever and they'll be like "I can't help it. It's just who I am. There's nothing I can do about it." As a matter of fact, I'd say that we have a whole culture of people who have autism, Asperger's Syndrome where we say that, where we put these walls, whether it's a result of subconscious conditioning or reinforcement from other people who have autism, saying the same thing, repeating the same thing, autism literature, we have the books on autism, saying these are the behaviors and there's no getting around that behavior, and then, there's all this in the media that says ya know this is how autism is, and so all of this is causing people with autism and Asperger's Syndrome to make excuses for their behaviors. (Alan, Subject #13)

Alan goes on to tell how to turn these negative attitudes into positive motivation later when talking about jobs, included as data as an answer to Research Question 5.

Hank, Subject #17, has experienced first-hand behaviors (or behavior differences) that have a negative impact. He uses self-discipline to minimize the negative consequences of those behaviors. The contrast in expectations can often be the root of conflict as seen through Hank's experience.

The worst of all is my wife and two sons. [laughter] I mean the more intimate the relationship, the more the aspects of Asperger's and autism begin to become a problem. I have an older son who's very sensitive and he's quite disturbed that I can't read his emotions. I keep telling him "Look, you gotta tell me what you're feeling; I'm not going to pick it up;" but his perspective is: "but dad, if you really loved me, you would know how I feel." So trying to get across to him "that's not the way I'm designed" I mean, it's not that I'm not compassionate; It's not that I'm not empathetic. Some people think that if you've got autism or Asperger's, you have no capacity for empathy. Uh, that's not really true. In fact the big frustration is: you feel the empathy, but you don't know how to get it out, and don't know how to make that connection, how that person's gonna receive it. You try to make a connection and you wind up saying something inappropriate or embarrassing and they end up walking away when you really want to connect with them, and that's been a real struggle, especially since I believe that people who are autistic or have Asperger's have an unusual capacity to relate to little

children and to animals, and to older people who have handicaps, especially mental handicaps; and so I had a wonderful relationship with my sons when they were little boys and then when they became teenagers, suddenly, everything changed, so that was a real challenge for me. (Hank, Subject #17)

Gary, Subject #22, brings up both his own emotions as well as the social consequences of where one chooses to attend college. He points out that the most important point is that you in fact go to college.

I've read a lot about Asperger's people that will go to a community college and there's nothing wrong with that and it really bugs me that I keep seeing references in movies, shows, people I know that say "Oh, this person went to a community college" as if that's not prestigious. For some of us, that really is the best that we can do and there's nothing wrong with that and if we have learning problems where that really is the best we can do, then what's wrong with saving money and, maybe staying close to home a little while longer? If that's the path that we need to take, then at least we're going to school at all. With grownups, school is an option, even if it takes us longer; even if it's not a prestigious school. I just feel like it's good that we're doing it, especially when you have learning difficulties and it's a challenge for you. I just think that you're good to get as far as you go instead of giving up.

I go to Phoenix University now because, so far, we've never done tests. So there's not really a way that I can fail with tests. A lot of people don't consider it a prestigious school, but I don't really care, because it's something that works for me. I tried every other way and there really isn't another way for me to get my bachelor's and I've accepted that. It's okay. I wanted to go to a more prestigious school, but it's okay, at least I'm in school and I'm happy about that. I really enjoy psychology and that's just the way that I'm doing it. (Gary, Subject #22)

Subject #14, Will's experience was not all negative, but there were certainly aspects of his experience that could have been better if he'd had current knowledge when he started his journey.

I got my grade 12 in high school. I wasn't in special education. I came up through the normal school system. I got my grade 12 although I took the easy courses to get through. I went to Kaplan University. I had to upgrade my grade 12 credits to get into the university transfer program – which I only took four classes and then quit because it was too expensive. (Will, Subject #14)

In the course of attempting to "look" normal, Alexa, Subject #23, found herself exhausting a great deal of energy and focus that she felt could have been used more effectively if society did not place so much value on how her disability appeared. She cites examples that, in her opinion, represent a broad spectrum of societal values.

I was thinking about function or high functioning in terms of autism spectrum disorders and probably other disabilities. Functioning doesn't actually mean what you think it would mean, it seems like it would mean telling somebody "Cool, like you're doing really well even though you have some trouble," but it actually means what the person looks like.

An example of this, like I sort of understand it: When I was in high school, I went to school with a kid who had an autistic brother and, I guess his mom must have met me at some point and, my mom recently talked to his mom because she was talking about that I was trying to get a job working with autistic people so she was trying to get his mom to suggest nearby places that I could go apply and she mentioned that I had Asperger's and his mom said "Oh, I would never have guessed Alexa had anything," and from the context, I assume this was supposed to be like a compliment or something, but it was sort of like when I was in high school, I didn't have any friends and I was kind of learning to, so I had some sort of friends and that was an accomplishment, I guess, but at the same time, I was very depressed and it was a lot of work, I guess to try and be normal and really friendly at school. It was kind of a goal I had set for myself and [to] go home and know that I had no friends and I was so tired and so I feel like that's cool you couldn't tell that I had something, and I'm sure your son didn't think about it either, but if he really thought about it, he would probably realize that there was almost no one in the school that he could count as being my friend so, how was I actually high functioning as a teenager if I didn't have any friends? Isn't that a symptom? (Alexa, Subject #23)

The following experience appears to answer Research Question 3 regarding interventions, but in the context of Alexa's description, she presents it more as a behavior pattern than an intervention. Therefore, it is included here as an answer to Research Question 4 regarding behavior patterns that had a negative youth with AS.

When I first went to college, my dad and I went to talk to some counselor 'cause we were worried I was gonna crash and burn possibly, so we went to the counselor and we sat down ('cause my dad obviously thought that I should practice talking rather than him talking for me). So, I was like "Hey, I have Asperger's. I'm just concerned that maybe everything will be really hard and I'll just do really bad throughout the whole term." So then the counselor was like, "Well, I don't think things are going to be hard because you don't look like you have Asperger's and you're looking me in the eyes and I'm sure everything will be good," blah, blah, blah ... It's not like he was saying he wouldn't support me if I had trouble, but he just tried to reassure me that I wouldn't have trouble because I was looking him in the eye, and, I don't recall saying "I'm afraid that I'm going to have a hard time this term because I don't look people in the eye." I recall saying, basically talking about anxiety and feeling overwhelmed which don't have anything to do with looking people in the eye, unless it makes you more anxious or overwhelmed in which case he shouldn't be encouraging me to do it more. So, this is another example. He doesn't really know what my issues

are and it's a bit patronizing for him to tell me that because I'm looking him in the eye, like those issues aren't there, and I think part of this is that it is just kind of human nature to assume that what you see is what's actually there. (Alexa, Subject #23)

Alan, Subject #13, provided a description concerning behavior patterns having a negative impact on AS youth, but his personal experience deserves its own category. Alan provides insight unlike any description in existing literature, and the depth and insight are haunting.

I really did not start making eye contact until the 12th grade and even then, my eye contact skills were not that great. One of the reasons is that it really uses up a lot of energy. It's very draining, as if you've been working for a very long period of time.

Another thing is when I was much younger, even until recently, I felt like [when] I was making eye contact, that people could see right through my soul and see everything there was to know about me. I felt, almost as if I was being raped on a spiritual level, so it was a very unpleasant feeling, a very disturbing feeling, and it just hurt, in a like spiritual way. I don't know, like, I just felt my soul just, just felt disgusting, having people make eye contact and I really felt like people could really just see me, and touch the inside of my soul and do terrible things to that. I think that other individuals with autism probably have a similar feeling to that. It probably just uses up a lot of energy and it probably just feels like you're violating them in a way, because that's kind of how I felt. (Alan, Subject #13)

Subject #13 described making eye contact in an unusual way. He told how it drained his energy, made him feel uncomfortable, spiritually hurtful, and most descriptively "emotionally raped." The outcome was avoiding eye contact in order to protect himself.

Tables 7 and 8 display many of the behavior patterns that had a negative impact on youth with AS included bullying by adults. Most of this bullying was done by teachers or other school staff. The ages of those bullied ranged from 5-years-old through college age students probably in their 20's. This bullying included everything from extreme intentional physical abuse to taunting by a college instructor. In each case, it left a life-long impact on the victims including decreased self-esteem, multiple school changes, avoiding social interaction and dropping out of public school. There were examples of teachers, aids and even principals acting as bullies. It didn't appear from the data collected that the long-term impact of their actions was a consideration. There were also examples of bullying by peers. Andrew, Subject #19, fought back and punched a bully in the nose. This helped Andrew's self-esteem, but he ended up changing schools because of the incident.

Table 7. Research Question 4a – Student Data – What Behavior Patterns had a Negative Impact on Youth with Asperger’s Syndrome?

Subject #	19	20	21	19	22	22
Subject Demographics	Male 24-30 UK	Female 18-23 Australia	Male 14-17 US	Male 24-30 UK	Male 24-30 US	Male 24-30 US
Interventions	Witnessed boy being thrown in the air & hitting head on concrete; Told he’d be aborted by staff member	Teacher stands her in front of class & accuses her of being rude & selfish rather than shy	Principal wanted to “knock him flat” so he’d grow again	Bully hit him in the arm all the time; Chased him around the desk	Requested teacher put test face down to avoid ridicule	Teacher saw smile on his face & requested that he share with class
Outcome	Pinned down a number of times	Treated like a freak for being different	Given up on the system; Home schooling & hoping college will be better	Andrew punched him in the nose in retaliation & got expelled from school	Teacher verbally harassed him for the request	Gary curtly said “no” & left her stunned

Table 8. Research Question 4b – Student Data – What Behavior Patterns had a Negative Impact on Youth with Asperger’s Syndrome?

Subject #	13	13	17	22	14	23
Subject Demographics	Male 24-30 US	Male 24-30 US	Male 40+ Canada	Male 24-30 US	Male 18-23 Canada	Female 18-23 US
Interventions	People using autism as an excuse for rude behavior, tantrums & low expectation of themselves or their children	Mother reinforced typical traits & deficits of autistic spectrum throughout his childhood	AS Dad does not perceive son’s emotional needs; Does not know how to show empathy	Social stigma propagated in media regarding value of “non-prestigious” college education	Took easy classes to finish high school	Judge the function of AS by how the person looks or makes eye contact
Outcome	Don’t make friends, reach their potential or irritate others	Took years to overcome effects & challenge himself to make progress	Frustration in personal relationships; Embarrassed when people give up & walk away; Seeing unreachd potential in relationships	Frustrated even though made logical choice to go to University of Phoenix	Had to upgrade courses to get into college	Ignores other signs of function

Some of the behavior patterns were self-inflicting, like those who used AS as an excuse to be rude to other people, refuse certain jobs, or just give up trying.

Some behavior patterns came from those close to the person with AS. Hank, Subject #17 for example, found it extremely difficult to communicate with his son who expected his father to have certain insights and when reality did not meet his expectations, he had little tolerance for a different relationship than he envisioned.

Alexa, Subject #23, had some insightful observations into how many people view “function” based on looks. Her insights revealed that because society in general expects her to appear a certain way, she invests a great deal of time and energy in making herself look neurotypical when she could accomplish more if she invested the same effort in how she functions.

Overall, the behavior patterns that had a negative impact on youth with AS tended to benefit only the person using the behaviors with little or no concern for the AS individual, or anyone else for that matter. It is the researcher’s opinion that the self-centered nature of the behaviors allowed the perpetrators to continue tormenting others over and over.

Research Question 5:
What Interventions and/or Behavior Patterns can be
Implemented Across a Broad Range of Youth with
Asperger’s Syndrome to Better Prepare Them to Succeed
in Academic, Extra-Curricular and Adult Life?

The data indicates the following interventions and/or behavior patterns that can be implemented across a broad range of youth with AS:

- Tell someone if you’re a victim of bullying
- Take children seriously if they tell you they’re being bullied
- Be patient
- Look for reasons behind frustrating behavior
- Define “high functioning” by behavior rather than appearance
- Pursue challenging employment in a positive environment
- Teach with more methods than lecture
- Adapt learning environment to student(s)
- Don’t out-guess diagnoses
- Adapt activities to student interests and abilities

See Tables 9 and 10 at the end of this section for a summary of these interventions and their outcomes.

Both the parent data and the student data contained a great deal of advice for other people in dealing with AS youth. Note this advice is given from those with AS, not parents, teachers or other leaders. Parent data is provided separately.

Annalissa, Subject #20, not only shared her experience with being bullied, but shared her thoughts on why people don't know bullying is happening and her advice on how to stop it. Bullying is only one of many answers to this question, but due to the prolific recurrence of this topic, it is important to include Annalissa's observations. There is a certain societal expectation of safety with teachers that is implied here, but was not provided.

And, you might be asking why people don't know about this? Well, the things is: your kids might be too scared to tell you; they might not really be thinking about what's going on and they might not realize till later in life that they were actually a victim of a teacher bullying them. And I'm not just talking about teachers telling you off, that's a whole different story if you've been naughty, it's like teachers just taking advantage of their power to humiliate a student. That isn't acceptable in today's world. Now people think "Oh, it's all right, corporal punishment's gone from schools." But, there's a worse sort of punishment that people objected to and that's like psychological bullying, emotional bullying from teachers. And, you could ask why is this acceptable? If hitting a kid isn't acceptable, why is this? I mean, it's not better. And, what can we do about it?

Well, the first thing we could do about it is: If you are a victim, it would be to tell someone, and if you have children, just take them seriously. Listen to what they have to say because they're not going to be lying about it, well some obviously will, but a lot of kids are victims of bullying and no one does anything about it because it's a teacher who's at fault and I just want to say that my heart goes out there to everyone who has experienced this or has been involved with it. I mean, I've been bullied at the hands of children a lot more, but that doesn't mean that the whole teacher thing isn't out there and that kids aren't being bullied at the hands of teachers either. (Annalissa, Subject #20)

Subject #16, James' advice echoes what experienced therapists are saying. He encourages those interacting with AS individuals to use patience and find out what factors are behind the behaviors. James' experience with his own family and their increased patience was presented earlier.

And the one thing I'll say to you all is: Be patient. Just be understanding and give support because what I will say to people is people with Asperger's you've gotta look beyond the obvious. You've got to look, well, 'why' did they do that? What's behind that? It's never somebody's just doing something to be rude or

somebody's doing something to be difficult. There's always something behind the behavior. That is what I've found and you just need that bit of understanding, that bit of support and that bit of patience, really, and that's something anyone of you guys out there can give to people with Asperger's and believe me, it makes such a difference and you know, all of you guys who are supporting someone who has Asperger's, you have the power to make that difference and I think that's a great thing. (James, Subject #16)

Alexa, Subject #23, describes many ways people can, and in her opinion, should focus less on the appearance of a disability and more on the function of a person. These quotes address specific things that can be done across a broad spectrum of people. Alexa recommends not annoying others, building confidence and functioning independently are all more important to her than appearance.

I think also the problem with defining high function this way is, people may be more concerned with looking normal than they are with other things. Like really, wouldn't it be better if I looked less normal and was better at planning and I didn't get so lost in my perseverations and stuff? And if I wasn't that worried about looking normal, I could probably do things more and jump into things more because I wouldn't worry as much about making mistakes that are really my issues. I know some people who are very Asperger's looking and some of these people are more successful than me both socially and academically. It shouldn't be so much about what people look like. It shouldn't be so much about whether somebody looks like a particular movie about Asperger's. Why do we always have to think low functioning is about how you look? Because how you look is one of the least important things about your life.

Another thing is we do live in a really able society where people are constantly so obsessed with whether a disabled person is getting in someone else's space or interfering with them or annoying them and because of that, I think people tend to really just think that Asperger's is about being an annoying person who is obviously different and talks too much or something. So if a person isn't troublesome for them to interact with, they don't, think they have anything and, I feel like the first thing anybody should want is to not be troublesome to other people, so I care very much about not being troublesome and whatever else is going on with me, I wouldn't be going around yelling it to people. So I'm trying to be polite to you, and as a result you're going to ignore the fact that I have issues.

When you think about the difference between girls and boys with Asperger's, the girls, you can't tell as well that they have it and they don't do all the monologuing and shit, or at least not as much, or they do it about normal things, instead of train schedules, but, they're more likely to be depressed and anxious and to not get married, so it's kind of interesting. What's funny is that maybe when people get to this point where they have figured out that the way

they talk is troublesome to other people and they get down on it. (Alexa, Subject #23)

Alexa shares her experience with executive function⁴ problems. This is a well-documented deficit in many with AS according to the literature and is, therefore applicable across a broad spectrum of AS individuals. Alexa's example of preparing in advance to go to the sandwich shop so she can appear "normal" is highly insightful, especially when she explains how exhausting it is for her.

I have pretty serious problems with executive functioning, I think and this is a major part of my life, but I constantly find myself thinking I shouldn't really be saying I have Asperger's. I shouldn't really be saying I have a disability because, today I went to the sandwich store to buy a sandwich and I had a perfectly normal talk with the guy and I never once really worried about where to put my eyes like I used to, and nobody asked me if I was doing okay because of the way I looked or something, and I didn't worry that I told him the things I wanted on my sandwich too fast or too slowly or that it took me a long time to do it because I had planned out before what I was going to say and I said it at the right speed so I don't really have any problems. But really, like how long did it take me to even decide that I was going to go to the store? How long to plan out what I was going to do? Like how hard is it really for me to figure out what I'm going to do every day and the put it into steps? It's like terribly hard. So, I mean, doesn't that matter? Does it only matter what I look like?

It's ridiculous that I'm so affected by this and, another thing [if] suddenly [some] ABA school put a camera in my room and they could see the way I move, I'm sure that I would be getting lots of electric shocks or whatever they do nowadays. It's like, what do people think: I read some website claiming though that the higher functioning people don't do autistic looking stims that we do some cute looking thing like tapping our foot, which, I don't think that's true. I pretty much jump – a lot – while kind of looking like this [staring up at the ceiling], and, I mean my parents always say that it's like living downstairs from an elephant because, whenever I get excited, I start jumping and they can hear me. When I went to college, my mom called me and was like "Alexa, I miss hearing you upstairs." [laugh] Which I think is cute. But this is such a big thing, but I forget about it constantly and I think that it's not a real symptom because it only happens in my room which I don't think the DSM says all symptoms must occur outside in full view of everybody. (Alexa, Subject #23)

Alan, Subject #13, encourages AS individuals to pursue challenging employment and not be scared off simply because there is a propensity for challenges in certain environments.

⁴ Executive Function: Delay in the ability to perceive the 'big picture' in order to plan, organize resources, prioritize and modify decisions based on results. (Attwood, 2007)

Alan advises people to avoid using their AS diagnosis as a crutch, but to use the knowledge of common AS traits to overcome the challenges they are likely to face.

You do not have to have a certain job. Ya know ... You can even be in a retail job that involves interacting with a lot of other people. It would be tough; and yes, there could be a great deal of anxiety, don't get me wrong! I'm very well aware of the anxiety issue because I worked a few months at Home Depot and I worked a little bit at the LA County Fair. I didn't like it necessarily, but ya know, I was able to hold a job, I was able to interact with all the people. We have this whole culture where we are now kinda saying 'what is autism?' and this is what we can and cannot do because we have autism or Asperger's Syndrome and, some of it is subconscious, so we need to pay attention to what we're saying to people. (Alan, Subject #13)

Will, Subject #14, talks about being able to get a job and contrasts the contentment of a working environment he can stand versus one he dreads.

Onto jobs: I work. I can easily get a job. I can put in resumes, cover letters, I can go through the job interview, I know how to play that script, except for I have major job anxiety, especially when I start a new job ... [tells about working with step-dad and being screamed at every day] My current job is an internship in an office setting. So far, that's actually working for me and I'm actually doing good without dreading every morning and fearing going to work like I did last year. (Will, Subject #14)

The researcher struggled with categorizing Subject #22, Gary's experiences to one specific research question. Gary's experiences are related here because of their broad application involving multiple symptoms of AS, multiple educational difficulties and perspectives that correspond with the existing written literature surrounding AS. Gary points out how his own learning style did not match the teaching style of many of his teachers. Individual learning styles should always be considered when planning teaching techniques. Minor modifications like silent rooms for testing may also be beneficial – and the students often know what works for them.

For people with Asperger's, or ADHD or reading comprehension problems, believe me, they want to be able to pay attention for a whole lecture! I would work very hard to be able to pay attention for a whole lecture, but it didn't mean that I could. I wanted to. Spoken monologues are the worst form of learning ever! And I found that in classes sometimes there'd be the rare class where everyone would make a speech or something and those classes would be the classes where I would learn everything because it was different people talking, different voices, different ways people would look, different ways people would describe things, and those classes I would learn the most, but lectures, oh my gosh, do I have a hard time with that!

And reading comprehension; and TESTING. I would always be the last person from taking a test. I would always double-check all of my answers and it was slow for me, and I realize now I really just needed to be testing in a silent room. I would've been able to concentrate so much better. You know, it didn't make me stupid, it just meant that some things took longer for me and there's nothing wrong with that and I think that it's just too bad when even grow-ups can't be a good example for being better about that, but from what I hear, a lot of teachers are in it for the wrong reasons, like summers off and stuff. If I was a teacher, I would definitely have a lot more patience with people that are clearly trying, but for some people, they just think: everybody learns the same way and if you work hard, you'll get it – and it's not necessarily true. Believe me, there were plenty of times I worked very hard and still failed a test and there's nothing wrong with that. Just do your best and there are ways that you can do things. (Gary, Subject #22)

Gary had many more experiences to share regarding his educational experience. He was forced to attend a small private Christian school. Other students have had opposite experiences. Since Gary only attended high school in one environment, there is no way to know for sure which would have been better for him, but he brings up several valid points that should be considered when selecting a school for someone with AS.

When I was younger, I was basically forced to go to a private school I really didn't like for a long time and I had to switch schools a couple of times. Mom pressured me to go there. Something that I would learn about my parents and Asperger's and neurotypicals was that: school's hard. School's hard in a lot of ways and I'm not talking about the social things here, I'm talking about the learning and the studies and I feel it was very confusing to my parents, to teachers, to classmates that even though I clearly was a smart kid and was articulate, and could express myself well, and read and write well; why is that I had so much problem with certain classes?

Just because someone might appear smart and be able to read and write well, does not mean that they're going to do well in every single class. I can tell you for sure, with like a history class and a physical chemistry class, I had an intense amount of trouble with names, facts, year numbers. Basically, if classes weren't interesting to me, it was very very hard for me to learn it. I could read sooo much on something and not know anything I read, especially on foreign languages like Spanish class. It was SO hard for me to learn and I had a teacher once tell me that he needed me to study more for my Spanish that if I would've studied for a couple of hours, I would've been okay for a test, and I told him "I studied for four hours yesterday" and it was the truth, I had. I still managed to just get like a mediocre grade on this test, but, anyway, I think that Asperger's people have reading comprehension problems to a degree.

I've had some learning difficulties, and I know that for me, it would have been better just to have gone to the same public school all throughout growing up

because I would've been able to stay in regular classes. I would've been able to get A's and actually feel good about my work. I would've been able to meet other very unique people like myself, and not, not feel like such an outcast in such a small school. I begged my mom SO many times that I leave that school. I was clearly having learning problems; they would study with me for hours and hours for the one history class, which was great of them to do that, but it wasn't necessary, all I needed to do was go to another school. There was once where I, a form you're supposed to fill out saying you're a Christian and stuff, well, the one year I looked at my dad and I said "Dad, I don't want to go here" and he says "What, you want to go to [my local high] School?" and I say "Yea" ... "JUST SIGN THE DAMN PAPER!" and I got freaked out and I signed it real quick 'cause all that was left was a signature, and I told myself the next year I'd rip the paper in half, but the next year I ended up getting sorta kicked out slash leaving, my horror story, but anyway, that's some thoughts about, I do feel like a public school would've been better, and the learning would've been better, the friends and the meeting people would've been better, meeting other unique people. It really kinda put me in my bubble box of just being too sheltered being in a private school and it made learning more difficult. For a lot of reasons I think people should be going to a public school if they have Asperger's. I think that there are probably more learning accommodations at a public school from what I've heard. There's a bigger likelihood you can go into a separate room to test and things like that where in private schools, they might have more tutoring time and stuff in some ways, but as far as having separate rooms for testing and accommodations for people with autism, I really would doubt that private schools would have that. Public schools would more be able to recognize learning deficiencies. From what I've seen at private schools, it would just seem that you're just supposed to learn what you're supposed to learn. (Gary, Subject #22)

David, Subject #18 had a variety of educational experiences with a variety of results. He also lived through the experience of his parents' divorcing and the subsequent financial struggles that resulted. He toughed it out and eventually pulled through. He did all this before knowing anything about AS.

Many teachers didn't want a special needs child in their class or didn't know how to help. One teacher said special needs such as ADHD "plus" are just an excuse for poor parents. [he shows a class picture] My parents were forced to either put me in self-contained special education classes or pull me out of school. They chose to home school me for nearly three years. Academics improved slightly, but social skills and communication didn't. Desperate for a solution, my parents sent me to a private school, paying with their credit cards. I made it a full year without being expelled or held back, just barely. The next year I got suspended, and I would have been held back if not for the liberal use of the "D-." Despite a great teacher the following year, and some academic progress, my cumulative bad behavior got me expelled.

My parents, who'd recently separated, officially divorced. No longer able to pay for private school, my mom put me back in public school. But, public school was different this time. Instead of one good or bad teacher for the whole year, we had choices of many teachers, some of which could understand me better than other. Bullies continued to be a problem. However, I got in less trouble and other kids started to accept me as "weird, but nice." Mr. Standley got me to join track and field. I never placed, but it taught me discipline and kept me out of trouble. I soon got me best report card ever. I failed math the year before, and would fail math the next year, but my teachers taught me that it's okay to fail as long as you keep trying. (David, Subject #18)

Randi, Subject #24, speaks to groups with Asperger's Syndrome. She was diagnosed later in life. At the time of this video, she was 45-years-old and is the mother of a neurotypical daughter. Randi gives the following advice that is applicable to a wide audience.

I was thinking today about what, um, the best thing a parent can give their son or daughter with Asperger's is, and it came quite clearly that the best thing you can give your son or daughter with Asperger's is: BALLS! I will explain. BALLS is an acronym that stands for: Belief, Acceptance, Love, Like and Support.

First of all Belief in themselves as a person. Inherent in having Asperger's is a lot of self-doubt and confusion, so you need to instill within your child a belief in their self; that they can be anything or do anything that they want to do or be. Also though, if your son or daughter, or other loved one is older, they might not have gotten their diagnosis for many many years, so when they tell you they have Asperger's, you might not initially believe them. It takes time to assimilate that information and to be comfortable with it, but don't doubt them, okay? As a friend of mine said, she's the mother of a, a young adult daughter with Asperger's and a lot of the girls in the family don't believe her, and she said to me, um, "What do they think a person with Asperger's looks like? Do they think they have polka dots all over their skin?" If you really want to know if someone has Asperger's, um, while they're sleeping, part their hair back there, and you'll find a little 'AS' carved in their skull, but apart from that, you'll just have to take their word for it. [laugh]

The second, thing you can give your son or daughter with Asperger's is Acceptance. Accept them for who they are. Accept, that they have Asperger's; that they always will have Asperger's. Don't berate them for having Asperger's. Don't try to change them with drugs because you can't cure Asperger's. The best thing you can do is just accept them for who they are, okay?

Love: That's the first 'L' in BALLS. Obviously, if you as a parent don't love your son or daughter with Asperger's, then there's going to be part of them that always feels like they don't deserve to be loved. Basic psychology. Okay? By the way, I am a parent. I am the parent of a non-autistic daughter.

The next 'L' in BALLS is: Like. It's easy to love someone. You know your child, a family member, and I hear people say all the time "I love you, but..." and then they proceed to criticize that person. To like someone is almost more important than to love them, ya know? When you like your son or daughter, it lets them know that they're likable, and we with Asperger's have a hard time with that; we're not socially accepted. There's a lot of confusion. We have all these issues that make us difficult to deal with sometimes, like the sensory issues, cognitive issues! Understand that you're looking at them through your lens, you know. Try freeing up your mind a little and looking at their behavior through their perspective; through an Asperger perspective.

The 'S' in BALLS stands for Support. We need support. I'm 45-years-old. I've learned how to do certain things, but there's still an awful lot I can't do and one thing I really can't do is fight my own battles or advocate for myself. I can speak for everyone else that I interview. I can speak for the world of Asperger's when I'm writing my books or when I'm meeting somebody or advocating for somebody or when I'm doing a workshop, but I still can't really fight my own battles. It's hard to, because we get confused; we get intimidated, and because if all those other elements are missing, we won't have enough faith in ourselves really, to fight our own battles. I know a lot of people with Asperger's cannot work, or have a very hard time working and supporting themselves, so a lot of you as parents might still be supporting your son or daughter, even though they're grown up, and I know that's hard for you too, but we do need support. Government agencies are clueless; disabilities services, agencies, etc. are largely, clueless. I mean here in New York State, if I wanted help, I'd have to go to the office of Mental Retardation! What a horrible name for a disability service; um, it should be Developmental Service or something like that, so there's a lot of things missing in this culture. There's a lot of things wrong. There's a lot of stigma. We could talk for ages about this, but we need support from our loved one, okay? (Randi, Subject #24)

Tables 9 and 10 highlight the fact that the data in this study was filled with advice for others: people with AS, for caregivers and family members, for school teachers and administrators. The advice was varied, but overall, it encouraged those teaching or caring for someone with AS to get to know them and adapt communication and teaching techniques to them. The advice also challenged those with AS to challenge themselves. For example, Alan, Subject #13, encourages those with AS to try jobs that might not seem like a natural fit and then stick with them while Will, Subject #14, describes how a positive work environment gives him encouragement to go to work every day and the self-esteem to succeed. Like the answers to Research Questions 1 and 2, the answers to this question focus on getting to know the child as an individual and adapting to them.

Table 9. Research Question 5a – Student Data – What Interventions and/or Behavior Patterns can be Implemented Across a Broad Range of Youth with Asperger’s Syndrome to Better Prepare them to Succeed in Academic, Extra-Curricular and Adult Life?

Subject #	20	16	23	13
Subject Demographics	Female 18-23 Australia	Male 18-23 UK	Female 18-23 US	Male 24-30 US
Interventions/ Behavior Patterns	Tell someone if you’re a victim of bullying; Take your children seriously if they tell you they are being bullied	Be patient; Look for the reasons behind frustrating behavior	Define “high functioning” by capabilities & behaviors rather than appearance	Pursue challenging employment
Potential Outcome	Opportunity to take action & investigate bullying situation; Allow children opportunity to find out bullying is not “normal” & should not be expected	Person with AS will feel more supported and be more calm, less agitated & annoying	Have more energy; Annoy other people less; Concentrate more on building skills	Open more employment opportunities; Build confidence; Increase capabilities

Table 10. Research Question 5b – Student Data – What Interventions and/or Behavior Patterns can be Implemented Across a Broad Range of Youth with Asperger’s Syndrome to Better Prepare them to Succeed in Academic, Extra-Curricular and Adult Life?

Subject #	14	22	22	18	24
Subject Demographics	Male 18-23 Canada	Male 24-30 US	Male 24-30 US	Male 24-30 US	Female 40+ US
Interventions/ Behavior Patterns	Attain a job in a positive environment	Modify teaching methods to include more forms than lecture	Adapt school and/or learning environment to student	Don’t out-guess a brain wiring diagnosis; Adapt activities to student interests & abilities	BALLS: Belief, Acceptance, Love, Like, Support
Potential Outcome	Look forward to going to work; Become a productive employee; Stay employed	Test in silent rooms; Better focus; Better retention; Better test performance	Better socialization, attention, performance; Less conflict & negative attitude	Improved grades & attendance; Improved self-confidence & attitude	Advocate when confused, intimidated or lacking in confidence

PARENT DATA

There were 10 Parent Subjects. All the Parent Subjects were selected based on verbal descriptions of interactions or interventions between their children and themselves, teachers or other adult leaders. Subjects #1 through #6 were all included in one video. Subjects #7 and #8 were husband and wife. Three videos of them were selected: One of each of them individually and two more with them jointly participating. Subject #10 posted an 18 minute video. The other parent videos ranged between six and ten minutes. Each video was transcribed word-for-word, then parsed into useful segments and analyzed for topics and AS symptoms. The most meaningful clauses were included in the findings.

OVERVIEW

In general, parents provided far more detailed information regarding interventions. They also provided more information about communication with therapists and teachers and gave synopses of long-term results of interventions. They did not talk nearly as much about friends, although they did talk about things that would help their children make and retain friends – almost like the infrastructure for friendship. They did not even mention bullying a single time in contrast to it being one of the most common topics in the student data. There is also a much heavier weighting to the parent data answering Research Questions 1 and 2, which are more positive, compared with the student data having a heavy weight answering Research Questions 3 and 4, which are more about negative issues. The parent data tended to take in the long-term progress and overall was more upbeat. The student data overall had a more sad or painful tone, even though many of the subjects were positive and acknowledged tremendous progress. This was determined by words, tone of voice and the personal nature of the stories they shared.

Research Question 1: What are the Interventions that had a Positive Impact on Youth with Asperger's Syndrome?

The data indicates that the following interventions that had a positive impact:

- Early intervention
- Speech therapy
- Try things

- Take kids everywhere
- Follow your intuition
- Use puppet theater
- Teach slang
- Build tolerance for sensory issues
- Chart everything
- Give students specific actions to vent anger and frustration
- Adapt teaching style to students
- Adapt teaching examples to interests of students
- Teach outside classroom
- Use technology tools, including iPad with appropriate educational apps

See Tables 11 and 12 at the end of this section for a summary of these interventions and their outcomes.

One mother who did not name herself could not say enough about early intervention or speech therapy. She was not the only parent to emphasize these two intervention topics. Early interventions, speech therapy and communication with teachers were repeated over and over by the parents.

Early intervention; early intervention; early intervention.

Speech therapy; and that doesn't just mean because if your child doesn't speak, it means to learn to have a conversation. I believe that Mark wouldn't be where he is right now if it hadn't been for all the early intervention. It didn't matter whether we were living in Florida, or we were in New England where he got speech therapy or we came back to North Carolina, but he was always being worked with to prepare him for society, real life – and he's made leaps and bounds. He would talk to himself a lot and I will tell you this, I met with the teachers all the time. We would, have meetings, at the beginning of the year, and if Mark would talk to himself, they had this thing where they would put their hand on his shoulder. I think the earlier you can start addressing it and start dealing with it, the better for you as a family and for your child. (Unnamed Parent #1)

There is no substitute for intuition and good judgment. Much of learning about AS is trial and error – and sensing what works when you find it.

The thing I would say about the therapies and all the things is that you still have to use your best instincts. Those are important. Read your child, and don't be afraid to try things. I think that one of the big things we did that was really great is that we took her everywhere! And we never hesitated even when it was a catastrophe; at the grocery store, at the restaurant, I mean she went places, and we

figured out how to make it work, and more specifically, we had one real place to go and that was speech. We went to a speech therapist in [our local city] and ya know, he was the right one – the right one. That’s so important because you’re going to end up learning as you go along that you have to find the right one and if it isn’t the right one then you change it; which we were very good at. (William, Subject #7)

William and Juliette, Subjects #7 and #8, watched the patterns of their daughter to figure out how to get her to communicate when nothing traditional seemed to be working. Their unconventional method did work.

We set up a puppet theater in our house because she didn’t want to talk to us; she wasn’t talking; so we became puppets. We bought lots of puppets; we have the puppet theater to this day because it was critical and William and I would get behind there and talk to each other and then we would ask her questions with the puppets and she would respond; so she was responding to puppets; so we felt like if we could take the speech therapy we learned or any kind of therapy that day and use it through the puppet theater to get [her] to respond back and forth, that was the beginning; and she wanted to respond to the TV, but not to us and so she would make a noise toward the TV, never to us, so the puppets were basically an icebreaker for us. We decided to go through comedy, ‘cause we felt like she had a good sense of humor; she was laughing at all the right things on TV, and so we thought, let’s build up the humor and that’s where the puppet thing I think really created her personality and being real funny and stuff. (Juliette, Subject #8)

Tonya, Travis’ mom, Subject #9 has found that interventions can be fun. She has just learned that some things are not easily absorbed and have to be specifically taught. In this case, the common trait of literal rather than implied meaning of language impacts Travis’ social interaction.

You have to teach them slang or dialect of their community. What does that mean? What is ‘tight’? You got on some ‘tight’ shoes. Uh, he’ll say, “No, my shoes fit actually fine.” ‘Tight’ in our community would mean, they’re cool; they’re nice. Right now, he’s tryin’ to wrap his head around ‘swagger.’ What is ‘swagger’? We all know ‘swagger’ is the way somethin’ moves, you know, but, he’s like “swagger? I don’t see him swaggering.” So, kids get a big kick out of that. (Tonya, Subject #9)

William, Subject #7, tells about an experiment that enlisted the assistance of other people – in this case restaurant owners. The restaurant owners turned out to be willing participants. William and Juliette tried this experiment over and over and eventually overcame many of their daughter’s sensory overload issues.

Every time we went to a restaurant when she was like 5-years-old, we said, “We have 20 minutes.” This is a white tablecloth downtown, [urban] restaurant. Most

people wouldn't even go there and we said "20 minutes. Can you guys get us in there and get us out?" and they said "Yeah" and 99% of the time they'll say yes. We did that everywhere we went. After 20 minutes, that was it: The kitchen noise was too much; she was too distracted by too many people; too much noise. Usually 20 minutes is a good amount of time. You can ask any parent that. We'd start out at 20 minutes; then we'd go to 25; then she'd get to 30; and she now sits through 3-4 hour meetings just fine, so I highly recommend you to get 'em out there and to try whatever you can. We had to prep her first. We had to prepare her with a picture showing her we were going to eat. We'd show her a picture of food and she's usually pretty hungry; it's kind of like a dog at 5:00 o'clock, ya know, it's like I'm gonna eat 'cause you're gonna give it to me 'n this is a good time so we would prepare everything to the time, and that doesn't work in everybody's life, but it worked for us and if you can just try it one day-a-week and then get your whole family on it, it'll work. (William, Subject #7)

Juliette, Subject #8, applied a herculean amount of self-discipline likely brought on by sheer desperation – and it paid off.

Everything we did we put down on paper, and we felt like maybe someday it will help somebody. She never slept, and then all of a sudden she started sleeping, so we would chart everything and say "Why did that happen? Why did she sleep through the night last night?"

You really have to stay firm with what you do and how you discipline at home, they better discipline the same at school – and wherever else she is, especially when they're younger. We happened to be in the school system when they allowed that where we could communicate with the teachers so [we] had a book every day and the teacher wrote down exactly what she did that day and we would write down exactly what she did that night. We were always on track with each other and we always felt like our teacher that was working with her one-on-one was on the same page as us, so that always helps.

We always wrote down every tantrum; then we were able to see what started the tantrum before it so as the day went on, we always had big sheets of paper that would cover an entire wall. Everything she ate that day, and everything she did all the way down to potty training told us a story, and if parents could do that, I don't recommend taking up your whole house, but it's a great way to track what started that tantrum. So, if we knew it was a pre-cursor or something that set her off by a noise or something like that; I was able to take sheets up to a year of her diet up to a dietician and have them tell me that she put herself on a diet that I'd never even heard of and the behavioral sheet was critical because it gave me the chance to find out, and then I knew exactly what was going on and why she was acting the way she was, and you can stop a lot of that, 'cause you've realized that she doesn't like this, she doesn't like that or whatever, so let's try to scoot away from those situations so it doesn't happen again. (Juliette, Subject #8)

Larry, Subject #10, provides specific examples of how communication with school teachers was successful. Working together, they came up with solutions. These solutions

could also have answered Research Question 5 because they are easily adaptable to other children in other situations.

Ya know, one of the examples we used with my youngest son was in kindergarten. He was having difficulty; he would get angry. So one of the things we told him, we said “Okay, Gavin, when you get angry, stomp your feet.” This particular day, I went to school to pick him up and the teacher came out and gave the universal ‘thumbs up’ sign, which means ‘he had a great day.’ So I gave the ‘thumb’ sign back and I said “He must’ve had a great day” and she said “He had a perfect day.” She goes “When he got angry, he stomped his feet. You would’ve thought he was one of those ‘River Dancers’ because he was stomping his feet all day long, but it worked.”

But what works today, may not work tomorrow with my kids as well, so we constantly are trying different things.

My older son Jason would get up and start pacing the room. Well, what they did for him, was they put a piece of tape at the back of the room so when he got ancy, he was able to get up and walk back and forth on that piece of tape. He didn’t disrupt anybody, and yet he was able to get up and walk back and forth. (Larry, Subject #10)

Larry also shared an example regarding learning styles rather than behavior. Keeping the AS children engaged in educational settings is a constant challenge. It is important to take the opportunities to “see what they’re thinking.”

I think especially for my son, and for some of the other kids I’ve seen and talked to, is that they learn totally different and unfortunately, they have a curriculum in the educational system and they’re supposed to follow it. But for Gavin, when he was in kindergarten, they had the math question: “ $24+16 = \text{what}$ ” and of course, he had ‘40’ written down and when they came up to him to ask him how he did it, he just said, “Well, it’s there” and they said “Well, yes, but you need to explain it” so he just said “Well,” he looked at the teacher and he said “In my mind, I saw 40 frames of film. I backed it up 16, and that left 24.” So that’s how he thinks, so I think as educators and as parents, we need to take [the] approach, okay, how are these children thinking and how can we build on their strengths? That’s how he thinks and because it is very frustrating for him when he has to show his work, I mean he can multiply things in his head faster than a lot of people can use calculators and get the number, so instead of penalizing him for getting the answer right, how can we as parents and as educators make it a positive thing for them? (Larry, Subject #10)

Many parents and teachers don’t have the knowledge base to perform this same intervention, but there are endless adaptations for individual students.

When my oldest son was in 3rd or 4th grade, they were doing the multiplication tables and they had to do them in a timed manner, and Jason knew the answers, but just was never getting it done under time. So, what would they do? They

would make him go to the classroom at lunchtime and do it. Well, all his buddies are out playing basketball and shootin' hoops, havin' a good time at recess; he's stuck in the lunchroom, or in the classroom. Well, that's not a very positive learning experience for him.

So I went to his teacher, I said look, "He's having difficulty taking it from hear [points to head] and putting it down hear [points to hand/paper] and you know he knows the answers." I said, "You know, just the other day I was out him and I said "Okay Jason, let's go over your multiplication tables." I said "If the Chiefs and the Raiders are playing football and the Chiefs score three touchdowns and the Raiders score two touchdowns, how many touchdowns have they scored?" He said "five." I said "How many points have the Chiefs scored?" He said "21." I said "How many have the Raiders scored?" He said "14." I said "How many have they scored all together?" He said "35." I said "Okay, now, I said if you if you and I go out and play golf and we both play nine holes each, how many holes have we played?" He said "18." I said "If we do it on the back nine how many have we played?" He said "36." I said "If we do the whole thing again tomorrow how many have we played?" He said "72." I said "Okay, you just multiplied 2x9, 4x9 and 6x9 or 8x9; alright and you multiplied 3x5, 2x5, and 5x7 so all of a sudden, I took a different thing, ya know, even though we were still dealing with numbers, I took something that really interested him, he was able to get those numbers and have them come up just like that."

So I told his teacher, "Take him out to the playground, let him shoot hoops, you ask him the questions and I guarantee ya, he'll go through that list faster than most students" – and it worked, and so those are the kinds of adaptations that we have to make as parents and I think as educators to help our students in the classroom. (Larry, Subject #10)

Teachers and parents are not completely alone in customizing educational activities. Computer technology applications are an ideal addition to the tool box caretakers have to adapt activities to students' abilities and interests. Debbie, Subject #25, has found the iPad, a computer tablet made by Apple, to be particularly engaging for children on the autistic spectrum. Debbie writes for a blog and reviews applications designed for the iPad. Debbie's 9-year-old son is autistic. She had heard about the iPad, but had been unwilling to invest the money to purchase one. She had the good fortune to win one in a raffle. She immediately began researching applications to use for her son. He took to it immediately, as she describes in her own words.

When I brought it home, I immediately went online and started looking up good apps for kids with autism, and good early learning apps. There's a really great site called MomsWithApps.com. They get all these sites that are recommendations, so I downloaded a bunch of them and started letting him go and it was just – just – I really couldn't believe it. That's the thing with our kids;

I mean we know that they're smart. The issue is: trying to find a way to go in there and let them express their unique intelligence – and this is something that [my son] has found is a gateway for him. I mean he's able to do things and show me things.

The things that have been great for [my son] are more the educational apps and sight word reading apps that just allow him to spontaneously engage with his environment and play and do things that he just never was able to do in a self-directed way before. He'd always need some sort of one-to-one guidance. [Video shows her son playing the *iWriteWords* app on the iPad]

One of the apps is called *FirstWords* and he can go right in there and drag around all these letters and form a word; it then says the word; it repeats it. It has a huge sequence of words and since he's a visual learner and he's not had a whole lot of success with phonics, with *FirstWords*, he's starting to do the kind of sight-reading that we've been trying to do for quite a while now it's reinforcing that beautifully.

Well, he's doing something we've never really seen him do before which is to explore. And because the interface made it so easy where you just tap/swipe tap/swipe and you just move around the screens to different apps. It's a pretty intuitive setup and I could see that he would just keep going back to certain apps like *FirstWords* and *ShapeBuilder* and *iWriteWords*, *TappyTunes* and all these kinds. And also, there's another one that is a social stories app called *Stories2Learn* where we actually make interactive audio-enabled stories about him and his day and things he does and he LOVES that 'cause it's all about him! (Debbie, Subject #25)

Many of the applications for the iPad were originally developed for either the iPod of the iPhone. Debbie has found that her son is more engaged when using the applications on the iPad. Debbie has found through her own research this is common with other children on the autistic spectrum as well. Debbie points out that technology devices like the iPad are a completely new option that were not available to the average person even two or three years ago.

In [my son's] case, he has problems with fine motor skills, so he can't manipulate his fingers with a high degree of accuracy and skill on a smaller scale that the iPod requires. He can do it, but it's just not the same for him and he finds it so much easier to manipulate the iPad because of the larger scale of the screen. That large scale touch-based interface is not something that had ever really been available on this kind of format for consumers with this kind of accessibility. Touch screens have always been kind of expensive and not portable. (Debbie, Subject #25)

Tables 11 and 12 show that the Parent Data revealed more specific interventions that had a positive impact on youth with AS than the Student Data. The specific interventions were modified for the individual child. Some of them were quite creative.

Table 11. Research Question 1a – Parent Data – What are the Interventions that had a Positive Impact on Youth with Asperger’s Syndrome?

Subject #	1	7	8	9	7
Subject Demographics	Mother of Son <9	Father of Daughter 15-18	Mother of Daughter 15-18	Mother of Son 10-14	Father of Daughter 15-18
Interventions	Early intervention; Speech therapy; Meaningful physical contact as a reminder / signal	Try things; Take them everywhere; Follow your intuition; Speech therapy; Don’t be afraid to change	Use puppet theater to communicate with daughter & apply speech therapy	Teach slang or dialect of local community	Enlist help of restaurant owners; Build tolerance to sensory issues a little at a time
Outcome	Early intervention gives more opportunity to modify behavior without negative behaviors forming habits; Prepared to converse, not just talk; Responded to subtle cues from teacher	Learned to adapt	Began to speak to parents; Developed sense of humor	Gain awareness of nuances in language used around them; Ability to communicate	Increased ability to tolerate noisy chaotic environments

Juliette also found it necessary to chart everything her daughter did for over a year. This dramatic intervention required day and night recording of everything from what she ate to sleeping patterns, to tantrums, to interactions with other people. The charts covered every wall of their kitchen. This intensive charting paid off in many ways as they worked with doctors, therapists and a dietician and figured out tantrum triggers, how to improve sleeping patterns, and discovered their daughter had put herself on a special diet. Juliette realizes it was extreme, but recommends it for challenging cases.

Larry, Subject #10, worked closely with his sons’ teachers to come up with customized techniques for both teaching and self-discipline. Separately, both boys had a

Table 12. Research Question 1b – Parent Data – What are the Interventions that had a Positive Impact on Youth with Asperger’s Syndrome?

Subject #	8	10	10	10	25
Subject Demographics	Mother of Daughter 15-18	Father of Son 10-14 / 19+ Daughter 15-18	Father of Son 10-14; 19+ Daughter 15-18	Father of Son 10-14; 19+ Daughter 15-18	Mother of Son <9
Interventions	Chart & record EVERYTHING	School teacher gave students a specific action to vent anger or frustration	Adapt teaching style to student	Adapt teaching examples to interests of students; Teaching outside classroom	Use iPad tablet with appropriate educational apps to adapt to individuals
Outcome	Discovered triggers for tantrums, sleep patterns & diet changes; Significant improvement communicating with doctors, dietician & teachers	Student adapted well; Self-managed; Less disruption to other students	Improved learning & performance; Improved attention	Improved attention; Improved performance	Engaged, self-directed, learned skills, had fun

method of handling boredom and frustration on their own without disturbing the rest of their class. One walked back and forth on a tape line at the back of the classroom; the other stomped his feet in place of angry outbursts. Larry tested individualized teaching techniques himself, then shared what worked with his son’s teacher. The teacher was very cooperative and the teaching techniques worked well.

Tonya, Subject #9, found it necessary to teach her son specific slang words common in their community. Her son did not pick up the nuances in the language as naturally as the neurotypical youth, but learned when specifically taught.

Similar to the Student Data, when the interventions focused specifically on an individual child, they were effective. One intervention is inherently individualized by design: technology devices. Debbie, Subject #25, described her research and her son’s experience with an iPad. He was engaged and self-directed from the very beginning. He explores and exerts self-control over the timing and use of the iPad. He is making progress with sight words and other educational concepts that were inconceivable without the iPad.

**Research Question 2:
What are the Behavior Patterns that had a Positive
Impact on Youth with Asperger's Syndrome?**

The data indicates the following behavior patterns that had a positive impact:

- Apply routines
- Notify children in advance of changes
- Adapt to individual learning styles
- Use technology reminders
- Use verbal reminders
- Teach social cues
- Share information
- Create discrete signals
- Share diagnosis with appropriate support providers
- Teach children to cope and rise to the occasion
- Don't over-compensate as a parent
- Use settings outside school to teach academic subjects

See Tables 13 and 14 at the end of this section for a summary of these interventions and their outcomes.

When answering this question, there was some overlap with answers for Research Questions 1 and 5. Subject #11, Karen Brown's insight into the value of routines fits best as a behavior because routine and structure in a child's life are more about consistency over time than about an intervention.

The thing that I learned that's most important about this is that they have to have a schedule. Routine is the utmost importance. If you don't have that, and there are changes that occur, the children have a really hard time with it. So everything has to be talked about in advance, and if you go and you change something, you have to let them know in advance. You have to get down to their way of thinking. Their brain is much more intelligent than our brain. (Karen Brown, Subject #11)

Travis' mom, Tonya, Subject #9, also talks about routine – and flexibility. She has learned about the value of consistency. She has also learned about the importance of adapting your teaching to the individual learner.

My son, Travis; he is a 9th grader and he attends ... County public school. A typical day is making sure that he get hisself ready at the right time. A lot of time, people with Asperger's, they're very inflexible, so you have teach them

flexibility. So, let's just say, if the black shirt's not ready, that's gonna be a problem, but he has learned through early intervention that you know what, things in life change. So, the person with Asperger's, you have to look at inflexibility. So when you're teaching, you have to be consistent and a very important thing is to find out how they learn. Are they visual learners? hands-on learners? exactly how much repetition they need? do they need role playing? Right now, the other thing is scheduling: He's able to do that on his own now; he feels really confident. (Tonya, Subject #9)

In addition to routines, there are many other reminders and consistencies that need to be taught – sometimes over and over.

My household is what I like to consider organized chaos. The wonderful thing about the technology age is that because I am not the most organized person in the world, I can put down appointments on my computer, and I always try to put 'em a day in advance so that way it always pops up on the screen, "You've got this to do tomorrow." That helps me out in my work and at home. Thank God for, answering machines, so that I'll leave a message at home so that way, I'll push the button and hear a message about what I need to do, also write it up on the calendar, those kinds of things. Especially with the Asperger's and autism, we have to plan things sometimes several days in advance; just the task of going to a baseball game, I may have to start two days before to prompt my son, "Okay now, on Wednesday you're playing ball at 5:30" and then the next day, in the morning, I'll remind him, "Okay, now today you're playing ball at 5:30," and then when he comes home from school, I'll remind him again that this is what we're doing because often times folks with ADHD and with Asperger's, though we're very spontaneous, we don't like spontaneity, and so, I know that doesn't make a lotta sense, but we are really spontaneous people where we'll get up and do something at the drop of a hat, but if someone else suggests it, then it kinda takes us out of our comfort zone and it can upset us. So constantly reminding my boys what needs to be done, and also, it helps me as a parent because I'm able to then remember what my kids need to do. (Larry, Subject #10)

Travis' mom, Tonya, Subject #9, also found that behavior patterns were critical to teach him things to compensate for his deficits in reading body language. She presents a highly visual example to show the differences between a neurotypical reading body language and her son.

As he progressed, we realized that socially, he doesn't quite get the social cues that everybody else does. So I, for example [Tonya grabs another person into the video and asks him to talk while she lays down on the table like she's completely bored] OK. See, Kevin stopped talking. My son Travis, he would continue to talk because he does not read body language. You have to teach them body language. (Tonya, Subject #9)

Behaviors are important at home, at school and in extra-curricular locations. Cooperation between parents, teachers and other leaders is critical to the healthy development of any AS child. Larry, Subject #10, sees the overall value in this cooperation.

For the most part, it's been a very very positive experience. The teachers in [our community] have been willing to work with us and they want what's best for their students and, fortunately enough, I'm in the business where I'm able to do research and find out information about autism and ADHD and, you know, if somebody comes up to me and offers me suggestions on how I can better serve my kids, I'm there with open arms because I want to make their lives easier and better for them. I take the attitude with educators and teachers that I as a parent have a tremendous amount of information, not only as in the mental health profession, but also, because I know my kid better than anybody else, and if I can offer the suggestions as to how to make my son's day better for them, then they're gonna have a better day and in turn, my son's gonna have a better day as well. If there's something that's going to make my son's life easier in the classroom where he isn't disrupting the other students, then it's also gonna make the life of the teachers [easier] as well, a lot easier. (Larry, Subject #10)

There are many ways to create a positive environment for children with AS. Larry, Subject #10, came up with signals that his son would recognize, but no one else would. This way, Larry avoided nagging and saved his son from public humiliation. A side benefit was maintaining a more positive environment for the entire team he was coaching.

I think one of the things that I've learned with my oldest son was that in soccer and I helped coach him because of his Attention Deficit Disorder, he would be out playing and, like any other 2nd or 3rd grader, if they're playing baseball, ya go to any baseball field in America where there's a 2nd or 3rd grader out there playin' right field and they're looking up at the sky and pickin' dandelions and throwin' rocks, but one of the things that I did with my oldest son is I said "I'll whistle and I'll give you the 'thumbs up' sign." I said, "Okay, that means it's time to refocus and pay attention to what's going on." I could've yelled at him and said "Hey! Get your head in the game" and those kinds of things, but I tried to make a more positive thing where not all the other kids would know that I'm telling him the same thing, it's just that 'it's that you need to focus and pay attention' and I did it in a manner where just he and I knew that and were able to communicate that. (Larry, Subject #10)

Parents are often very concerned about sharing the AS diagnosis with other people. They want to seek out safe environments for their children and avoid ridicule or unnecessary bullying. This mother has found sharing about her son's AS to be an asset and encourages other parents to do the same.

As a parent, you're continually working to balance preparing your child to deal with the world and helping the world understand your child. That might include

sharing information with teachers, classmates, ... educators, bus drivers, janitors, you really have to cover the whole field and just make sure that they understand it and leave it open that if you have any questions, absolutely call. (Unnamed Parent #2)

There is always need for balance in parenting. This mother is always walking the fine line of too little and too much.

What I'm trying to do most of all, is not over-compensate. I don't want her to think that the world's going to accommodate her, so I'm trying to help her learn to cope and how to rise to the occasion. (Unnamed Parent #3)

Larry, Subject #10, uses an intervention here to describe an effective behavior pattern. He explains how these patterns benefit the children and increase the learning of those on the autistic spectrum.

I think leisure plays a very important role. Number one, you're taking them away from the quote/unquote 'academic setting,' so, for instance, my son loves to fish and there's a part in his curriculum in science on ecology so I read over the book and then we went out fishing and we talked about ecological issues and the food chain and picking up trash and the damage the trash can have on an eco system and all those kinds of things. So while you're teaching them, and teaching them what they need to know in the school, it doesn't seem like it's educational so they're not near as stressed and the thing is, if you're doing something that you enjoy, and you're learning something at the same time, you're more than likely gonna retain that information a lot easier, than [if] you're doing something that you're forced to do, that you don't like, and you're forced to learn those kinds of things. Leisure plays a tremendous role. (Larry, Subject #10)

Tables 13 and 14 show that when describing behavior patterns that had a positive impact on youth with AS, three of the Subjects described behaviors that involved routine and reminders. One common trait associated with AS is a difficulty shifting attention. Larry, Subject #10, has found that electronic reminders for him and then multiple reminders for his sons help compensate for this known challenge. His son has an easier time being prepared mentally and physically when it is time to go somewhere. Larry has also found that multiple reminders starting a day or two ahead, lessened melt-downs and created a more positive and cooperative environment.

Sharing information was also a behavior pattern mentioned by multiple Subjects. Sharing information with teachers and others who have a responsibility for or a vested interest in a child, benefit by any knowledge about the child. In most cases, this is beneficial

Table 13. Research Question 2a – Parent Data – What Behavior Patterns had a Positive Impact on Youth with Asperger’s Syndrome?

Subject #	11	9	10	9
Subject Demographics	Mother of Son 15-18	Mother of Son 10-14	Father of Son 10-14 / 19+ Daughter 15-18	Mother of Son 10-14
Interventions	Routine; Tell them in advance of any changes	Routine; Adapt to learning style; Early intervention	Use technology reminders; Remind kids several times to mentally prepare	Teach social cues
Outcome	Less mood swings	Builds confidence; Can function on his own	Keep everyone on schedule; Avoid tantrums	Adapt to social settings

Table 14. Research Question 2b – Parent Data – What Behavior Patterns had a Positive Impact on Youth with Asperger’s Syndrome?

Subject #	10	10	2	3	10
Subject Demographics	Father of Son 10-14 / 19+ Daughter 15-18	Father of Son 10-14 / 19+ Daughter 15-18	Mother of Son <9	Mother of Daughter 10-14	Father of Son 10-14 / 19+ Daughter 15-18
Interventions	Share information between parents & teachers	Create a symbol to refocus attention that others won’t recognize	Share diagnosis with anyone who can support your child; Make sure they understand its meaning	Teach child to cope & rise to the occasion; Don’t over-compensate as a parent	Use settings outside school to teach academic subjects
Outcome	Makes life better & easier for teachers & students	Alleviates social embarrassment; Keeps him focused	More supportive environment	Child is prepared for the real world	Children remember applied learning

to the child. Communication with teachers proved to be extremely beneficial for the Subjects in this study.

Subject #3 makes a habit of teaching her daughter skills that will make her more independent. This focus on skills her daughter would need in the future showed a thought pattern of preparation that influenced her behavior.

Larry, Subject #10, found that teaching and reviewing academic topics in non-school settings was particularly beneficial. His son learned better and retained his academic subjects. The more these behavior patterns were tailored to the individual child, the more effective they appeared to be.

Research Question 3: What Interventions were Used that had a Negative Impact on Youth with Asperger's Syndrome?

The data indicates the following interventions that had a negative impact on youth with AS:

- Don't push organized sports if child is not adapting
- Find activities to fit individual child
- Get diagnosis early

See Table 15 at the end of this section for a summary of these interventions and their outcomes.

Although the parent data was far more heavily weighted toward the positive interventions and behaviors, Larry, Subject #10, shared one vivid experience with his son Gavin. Try as they may, organized team sports were not a positive lived experience for Gavin. Larry was obviously working to negate the negative impact and apply life learning to this experience.

Once again, we kind of go back to the school setting and we also go to the leisure and recreational setting; not all kids are built or want to participate in recreational programming. For instance, my youngest son Gavin has had a difficult time, even though several years I coached him in organized sports. ... For kids with autism and with Asperger's, if you're in a setting where it's very very noisy, that's just like taking your fingernails and running them down a chalkboard, and that really really, bothers them. So why would you put someone in a situation where it's going to be very difficult for them to be successful? So, we try, and we'll continue to try that maybe one of these days he'll find that he'll maybe be able to do throughout his lifetime, but, right now, it doesn't seem like team sports are that. Perhaps we'll try swimming or something like that, but right now, but it's a trial and error basis. I don't ever say "Don't do something" because you never know when it might click and it might work. (Larry, Subject #10)

One other father shared the sadness of not knowing about AS. The intervention of a diagnosis and specific teaching to his son's deficits.

If we could've found out about his diagnosis early, it would've avoided so many years of pain and anxiety, and I think he could've learned things more specifically about social skills. (Unnamed Parent #4)

Table 15 shows that the Parent Data only revealed two specific interventions that had a negative impact on youth with AS. Larry, Subject #10, found that organized team sports

Table 15. Research Question 3 – Parent Data – What Interventions were Used that had a Negative Impact on Youth with Asperger's Syndrome?

Subject #	10	4
Subject Demographics	Father of Son 10-14 / 19+ Daughter 15-18	Father of Son 15-18
Interventions	Don't push organized sports if the child is not adapted; Look for activities that fit the child	Get diagnosis early
Outcome	Child will have more confidence & enthusiasm for activities	Avoid pain & anxiety; Learn social skills

were more torture than positive influence on his son. This depends on the child and Larry found that the appropriate activities need to be evaluated for each child. The right activity builds confidence and captures the passion of the child. The wrong activity creates frustration.

Subject #4 warns of the down sides of avoiding a diagnosis. Many parents fear labeling a child. They are afraid the label will create more problems for the child. This parent cautions about the downside of that outlook and suggests that the benefits of an early diagnosis far outweigh any negative effects of a label.

**Research Question 5:
What Interventions and/or Behavior Patterns can be
Implemented Across a Broad Range of Youth with
Asperger's Syndrome to Better Prepare them to Succeed
in Academic, Extra-Curricular and Adult Life?**

The data indicates the following interventions and/or behavior patterns that can be implemented across a broad range of youth with AS:

- Teach life skills
- Use social skills training
- Get a diagnosis
- Get support your child needs
- Educate yourself about diagnosis – and related syndromes

- Communicate with teachers
- Work together as a team with teachers
- Be your child's advocate

See Table 16 at the end of this section for a summary of these interventions and their outcomes.

Both the parent data and the student data contained a great deal of advice for other people in dealing with AS youth. It should be noted that the following advice is given by those who are parenting children with AS.

Sometimes it is the simple things that are the most important to teach for success in adult life.

I try really hard to encourage her to develop life skills, even when it's scary for her; basic things like paying bills and, now she's learning to drive a car, things that developing kids are doing. (Unnamed Parent #5)

Collin, Subject #15, talked about social skills training in the student data. This father concurs that this kind of therapy is beneficial no matter what variation you choose.

Individuals with Asperger's Syndrome often don't pick up expected social behaviors by watching others, so it helps to demonstrate those behaviors and have children or teenagers or adults practice them. Our son benefited by a social skills group led by a therapist during his school lunch hour. There are also tools and techniques you can use at home. (Unnamed Parent #6)

Diagnosis is an enormous topic all of its own, but Tonya, Subject #9, gives a brief piece of advice from her experience with Travis.

As far as in his classroom, Travis is on the very mild end. His disability could have slipped through the cracks. The first thing parents should do is get a neural psychological exam because all of these things are derived from the wiring of the brain. Once you figure that out, then you need to find out what those areas are: Is it speech? Is it language? Is it cognition? Is it acuity? What is it and then get that child the support that they need. (Tonya, Subject #9)

Larry, Subject #10, brings attention to the fact that once you have a diagnosis, you must continue to learn and educate yourself in order to help your child.

It took a while for us to get that autism, educational autism diagnosis, but once we got that, that was something that even though it added another acronym to his name, we were pleased to find out what was causing him to have difficulty in school, with his peers. So that's really helped, and I think that's one of the things that parents need to do is to look maybe beyond what the original diagnosis is and they need to educate themselves about Attention Deficit Disorder if that's what their child has been diagnosed, and find out other things; find out what other

disorders there are that may have similar traits so then that way when a child gets older and things may happen in the classroom that didn't happen when they were in kindergarten that they might be able to put a finger on "Well, my child may have Asperger's or may have autism," so the parent themselves needs to educate themselves regarding the disorder to help their child. (Larry, Subject #10)

Larry encourages parents to share what they learn with their children's teachers.

I think it's important for parents to educate themselves so they know about the disability so when they go in and talk to a teacher, that they can explain what's going on in their child's life. The old adage that 'you can attract more flies with honey than you can with vinegar,' and if you go in and you provide that information to the teachers, it's gonna make their lives a whole heck of a lot easier and in turn, they're going to learn how to deal with your child, and they want to make it a very positive learning experience for them. I haven't had any troubles whatsoever. (Larry, Subject #10)

Larry's final advice is to never give up – to be your child's advocate and stay involved.

Number one: Don't be afraid to ask questions! Because, the more questions you ask, the more informed you're gonna be. Don't be afraid to take 'no' for an answer because it's your child and you want to do what's best for your child. Be educated, but don't force your opinion necessarily on the people you're trying to work with. Give 'em your opinion; empower them; have them help you in the decision making process so you're working together as a team. It is a team effort; it's you, it's your child, and it's the therapist or the educator and if they're not all working together, then it's not gonna work, the machine isn't gonna work, but if you're all working together, the bottom line is to do what's best for the child. If you can make your life easier or your child's life easier and the mental health professional or the educator's life easier, then the child's life is gonna be a whole heck of a lot easier too. (Larry, Subject #10)

Table 16 highlights that like the Student Data, the Parent Data revealed advice to others to answer Research Question 5. Subject #5 encourages teaching life skills that neurotypical kids are learning like driving and paying bills. Subject #6 encourages the use of social skills training led by a therapist. This correlates with the findings of Subjects #15 in the Student Data.

Tonya, Subject #9, strongly suggests getting a diagnosis and understanding the brain wiring of your child. Tonya believes that once you understand the brain wiring and what the diagnosis means, you need to seek the services your child needs. Tonya believes this is especially important for higher functioning AS children who may otherwise fly under the diagnostic radar and miss getting the assistance they need.

Table 16. Research Question 5 – Parent Data – What Interventions and/or Behavior Patterns can be Implemented Across a Broad Range of Youth with Asperger’s Syndrome to Better Prepare them to Succeed in Academic, Extra-Curricular and Adult Life?

Subject #	5	6	9	10	10	10
Subject Demographics	Mother of daughter 15-18	Father of Son 15-18	Mother of Son 10-14	Father of Son 10-14 / 19+ Daughter 15-18	Father of Son 10-14 / 19+ Daughter 15-18	Father of Son 10-14 / 19+ Daughter 15-18
Interventions/ Behavior Patterns	Teach life skills: pay bills, driving, etc.	Use social skills training led by therapist; Demonstrate behaviors	Get a diagnosis; Determine the specifics that impact your child; Get the support your child needs	Educate yourself about the details of a diagnosis & pay attention to symptoms as the child develops	Communicate with teacher; Share opinions to empower them; Work together as a team	Be your child’s advocate
Potential Outcome	Develops confidence, prepares for independence	Develop social skills, practice tools & techniques at home	Child will adapt to life better & learn better	Less frustration; Early diagnosis; More appropriate interventions	Easier for teacher when they know more about the child	If the teacher’s life is easier, your child’s life is likely to be easier too

Larry, Subject #10, encourages parents to continue investigating and learning about the diagnosis your child receives – and other related syndromes. There is a strong tendency for overlapping syndromes with AS, like ADHD. This may complicate treatment. Proper diagnosis may evolve over time. Larry also strongly encourages open communication with teachers and empowering teachers to try new techniques that may work with your child. Larry believes his strong advice to be your child’s advocate will make your child’s teacher’s life easier and in turn, make your child’s life easier.

The end result is: once again, adapting the diagnosis, education, communication and treatment to the individual child is what makes it effective.

MOTHER AND SON DATA SET

The single parent/child data set is an example of the marked differences between the parent data and the student data. Shane Brown is now a teenager. Karen Brown has been fully aware of – and has been living this experience for well over a decade. Although this parent/child dyad is not typical for this study, it is used here to highlight the distinct

difference in perspective and to display the kind of language and shared experiences that are typical of the parents vs. those who had AS themselves. It is a clear distinction since the two descriptions are referring to the same young man.

The following is Shane's mother's description of their experience.

So Shane was two when I noticed first that he had symptoms that something was amiss. The symptoms were: banging his head on the floor, pulling kids' hair, not being able to control his temper, and struggling in school.

The formal diagnosis came when he was nine and I took him to a pediatric neurologist. In the beginning, before I understood what was going on and he would act up and behave [badly] in public, I was very, embarrassed, angry. I didn't understand; I had a hard time with it. Once he was diagnosed, it was sort of a relief because it put a picture of why he was behaving the way he was behaving.

The neurologist, my husband and I worked together. The three of us came to the decision that we did not want to medicate because of the side effects and because we felt that that's not the way we wanted to go for Shane. We went with the choice of speech therapy, occupational therapy, adaptive physical education, to strengthen him without medication. (Karen Brown, Subject #11, mother of Subject #12)

The following is Shane's description of their experience.

I really didn't notice the symptoms until my parents had me diagnosed. All my life I've had a pretty bad memory. I can remember certain things, but sometimes I remember the important things; sometimes I remember really random facts.

I really don't remember anything about my reaction to when I found out I had NLD. I mean it wasn't a big deal to me. I barely understood what they were talking about.

I believe even before we found out, that I had NLD, I was having, occupational therapy (OT) and adaptive physical education (APE). So I had normal PE and APE. And at OT they would take me out and work on my motor skills, on my writing.

My friends and family most likely gave me the most emotion and moral support. I mean the principals of my schools, the Occupational Therapist(s), the therapists were always there if you needed them. If you needed your therapist, you got your teachers to call them, the OT would probably come and get you once or twice a week. My mom is probably responsible, no definitely responsible for all this! She's fought for me over the years; fought to keep me having OT; fought to keep me having IEP, my APE, keeping therapists. So my mom's helped me a lot.

When I found out, it didn't really affect me that much. I still keep like who I am, just a normal kid. So I have NLD, no big deal. (Shane Brown, Subject #12, son of Subject #11)

The parent data differed substantially from the student data. Karen and her husband had many difficult decisions to make and faced continual challenges. Shane barely knew there was a problem. Life seemed normal to Shane. Seeing such a difference evolve in the data provided an opportunity to divide the findings into two major sections for analysis. The first section describes the student data and the second section describes the parent data.

SUMMARY

Dividing the findings into student data and parent data provided an opportunity to analyze the data from two completely different perspectives. Overall, the student data provided substantially more answers to Research Questions 3⁵ and 4⁶ which addressed interventions and behavior patterns that had a negative impact. Research Question 3 revealed five answers from the student data and only two answers from the parent data. Research Question 4 revealed 12 answers from the student data and no answers from the parent data. This difference of 17 to 2 is dramatic – 8.5x difference. This is likely due to the long-range perspective of the parents seeing the impact of the therapies vs. the personal experience and shorter perspective of the students themselves. The researcher's opinion as to why this chasm is described at length in Chapter 5.

Overall, the parent data provided substantially more answers to Research Questions 1⁷ and 2⁸ which addressed interventions and behavior patterns that had a positive impact. Research Question 1 revealed five answers from the student data and 10 answers from the parent data. Research Question 2 revealed five answers from the student data and nine from the parent data – nearly double for the two answers combined.

⁵ What interventions were used that had a negative impact on youth with Asperger's Syndrome?

⁶ What behavior patterns had a negative impact on youth with Asperger's Syndrome that could have been changed based on current knowledge?

⁷ What are the interventions that had a positive impact on youth with Asperger's Syndrome?

⁸ What are the behavior patterns that had a positive impact on youth with Asperger's Syndrome?

While separating the data provided an opportunity for analysis, combining the two perspectives provides a comprehensive view that covers a broad perspective of the overall lived experience. The implications of this broad perspective will be analyzed in more detail in Chapter 5.

CHAPTER 5

DISCUSSION

The overall purpose of this study was to survey the personal experiences of individuals with Asperger's Syndrome (AS), analyze and combine them to come up with a shared lived experience. It is the researcher's belief that an examination of the shared lived experiences of people with AS can provide information pertinent to treatment, intervention, and assistance across a broad range of the AS population, and yet still be meaningful to the AS individual in daily life – and be particularly helpful in educational and extra-curricular settings. While there were many detailed discoveries that came from the data collected, the overall theme that emerged from the data analysis was that the most important things in educational, extra-curricular and parent environments involving youth with Asperger's Syndrome is to get to know each child as an individual, treat them with respect and dignity, and find what works for them as an individual, rather than censuring them for not conforming to neurotypical expectations. Every other factor remains secondary to these.

This study analyzed data in the public domain available via the internet and accessed as if it were in a research library from social media websites. YouTube was the primary source for video monologues recorded by individuals with Asperger's Syndrome (AS) and parents of those with AS. Video monologues were selected and transcribed. Using a phenomenology research method (Dukes, 1984; Guba & Lincoln, 2005; Polkinghorne, 1989; Reimen, 1986;), the researcher found comprehensive statements about how individual participants have experienced life with AS (Creswell, 1998) and combined those statements to create an overall "lived experience" of the individuals. The intent of this phenomenology study was to identify common interventions and patterns of behavior used by teachers, parents, or other adult leaders that assisted AS youth to adapt to neurotypical environments at home, school, and other extra-curricular settings.

RESEARCH QUESTIONS ANSWERED BY THIS STUDY

- 1) What are the interventions that had a positive impact on youth with Asperger's Syndrome?
- 2) What are the behavior patterns that had a positive impact on youth with Asperger's Syndrome?
- 3) What interventions were used or not used that had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic environments and adult life?

INTERVENTIONS AND BEHAVIOR PATTERNS WITH A POSITIVE IMPACT

Research Questions 1 & 2 investigated interventions and behavior patterns that had a positive impact on youth with AS. There was a clear nuance throughout the 25 video monologues included in this study of help and assistance for others in the AS community. This was true of both the Student Data and the Parent Data.

There was a difference between the Student Data and the Parent Data in the focus of the interventions and behavior patterns that had a positive impact on youth with AS. The Student Data focused more on short-term interventions and their results whereas the Parent Data described interventions from a longer-term perspective – sometimes over several years. This long-term perspective innately allows for a more positive tone because the parents have had years to observe their child's growth and maturity along with the effectiveness of therapies and other interventions.

Parent Data

Early intervention was something stressed repeatedly in the Parent Data. Early diagnosis sets realistic expectations for parents thereby lowering their stress level and creating less conflict in the family. Parents clearly saw the benefits in finding out about AS and working within the known common traits and behaviors of AS, rather than being frustrated by a child who was different. They found value in helping their children navigate a neurotypical world from a young age. They helped minimize unhappiness and frustration

by finding the areas that were most challenging for their children, seeking out therapies and practicing behaviors, then finding appropriate opportunities for engagement based on their child's ability to cope and adapt. Parents found that doing this for their children at a younger age not only built skills and tolerance, but increased their self-esteem and confidence. Confidence led to more social engagement, more opportunities to practice their coping behaviors and work with sensory issues, especially before age 11 or 12 when their peers were more socially forgiving, and they had more courage to go into the world and attempt new activities. The parents also learned to accentuate the child's gifts, rather than dwell only on the behavioral abnormalities which further reduced tension in the family and often led to the child having more social interaction with peers with shared interests (Bashe & Kirby, 2005; Grandin & Barron, 2005; Hall, 2001; Higgins, Bailey, & Pearce, 2005; Irvine, 2011; Jackson, 2002; Robison, 2011; Saperstein, 2010; Szatmari, 2004).

Speech therapy was one of the specific interventions recommended by parents. Several parents discussed not only the value of speech and pronunciation, but of conversation and nuances of language. Social Skills Training complemented speech therapy. Therapeutic Social Skills Training included recognizing facial expressions, staying calm in group settings, fitting in with peers, avoiding ridicule and potential bullying, and in the end, making and keeping friends (Grandin, 2011).

Parents also discussed interventions and behavior patterns from a more managerial, rather than an emotional perspective. This is not to say the parents were not emotional; in fact, they were quite passionate, but they tended to describe a need, and then tell how they went about filling that need either by themselves or by seeking out professional assistance. Parents also provided "before and after" snapshot descriptions to assess the effectiveness of the interventions and the long-term impact on their behavior.

Parents talked about many different types of interventions. Some interventions were very creative and customized, like requesting high-end restaurant owners to have prepared an entire meal so the family would spend no more than 20 minutes in the restaurant. This helped minimize sensory overload. Another example not found AS literature was using a puppet theater to teach speech and social interaction with parents. The parents watched their child and tested something they thought she would respond to based on her behavior as an individual, not a diagnosis.

Some interventions came from sheer desperation. AS has so many disparate symptoms and is impacted by so many neurological, environmental and nutritional factors that it is nearly impossible to correlate all the variables and isolate those that trigger certain behaviors (Armony, 2008; Bortfeld, 2010). Subject #8 discovered that charting all aspects of a child's life together in a visual format was the only possible way to receive proper treatment – even when it consumed every wall of her kitchen for over a year.

Not all of the interventions were as dramatic or unconventional as those described above. Two-thirds of the quotes that answered Research Questions 1⁹, 2¹⁰ & 5¹¹ (12/18 for Research Questions 1 & 2 and 4/6 for Research Question 5) in the Parent Data referred to communication and cooperation with school teachers. As parents of an AS child, they found school teachers to be some of their most important allies in preparing their children for a more positive future. They formed a day-to-day partnership with teachers and communicated with them regularly. It is well documented in the literature that routine is important to people with AS (Bashe & Kirby, 2005; Frith & Happe, 1994; Grandin & Barron, 2005; Hall, 2001; Jackson, 2002; Saperstein, 2010). This study confirmed that routine combined with flexibility to accommodate the individual, sensory issues and learning styles, is critical to successful interventions.

Technology was particularly useful with communication and reminders. PDAs, electronic calendar reminders, voicemail, text messaging and e-mail combined with verbal reminders and prodding were highly recommended by parents. People with AS become hyper-focused and have difficulty shifting attention, so catching them by surprise or changing plans at the last minute is known to induce emotional instability (CETV, 2008; Grandin, 2011; Jackson, 2006; Robison, 2011). Technology is also an exceptional tool that allows for customization and replication and creates an extension of human resources. This

⁹ 1) What are the interventions that had a positive impact on youth with Asperger's Syndrome?

¹⁰ 2) What are the behavior patterns that had a positive impact on youth with Asperger's Syndrome?

¹¹ 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic environments and adult life?

is critical for both families and school districts with limited budgets (AutismHangout, 2010c; Bailey, 2011).

One specific technology intervention that continues to be recommended, especially for younger children on the Autistic Spectrum, is a tablet device made by Apple Computers called the iPad. Many of the applications for the iPad also run on other Apple devices like iPhones and iPod Touches, but they seem to have far more impact with AS children on the iPad. It is theorized that this is because the touch screen is bigger and requires less precise dexterity. The bigger screen also seems more life-like. Whatever the scientific reason, the emotional connection is there and the children are using iPads. Many of the “learning apps,” as the applications are referred to, are highly engaging and therapeutic. The apps are intuitive and flexible and there are a variety of apps for different educational needs. The educational and therapeutic use of apps is more limited for older children and those who are higher functioning (Autism Hangout, 2010c; Bailey, 2011). A spreadsheet of tested and recommended apps as of the time of publications has been included as Appendix D.

There are many things that neurotypical youth seem to learn just because other people around them do the same things. Youth with AS often require specific coaching to learn some of these same skills (Attwood, 2007; Baron-Cohen & Jolliffe, 1997; Grandin, 2011; Robison, 2011; Simone, 2010). The Parent Data revealed the need for life skills like hygiene, paying bills and managing finances, driving, doing laundry and other skills that comprise independent living.

Next to early intervention, parents and educators adapting to the AS individual was the most consistent theme throughout the Parent Data and impacted the results of every intervention more than anything else.

Student Data

Students, on the other hand, tended to describe in far greater detail the actual lived experience while they were living it, even if it happened in the past. When students talked about an intervention, they did not talk about how the intervention came about or much of a before and after view. They did, however, share how it felt, what it meant to them and significant advice to help others with AS avoid potential misery from similar situations. Students described in great detail what it was like to interact with people and what was

emotionally challenging and enlightening. They were grateful for people who were patient with them and helped them. There was a much larger focus on friendship and relationships in general in the Student Data.

The combined data analysis from Parent and Student Data revealed the following interventions and patterns of behavior that had a positive impact on youth with Asperger's Syndrome:

- Making eye contact
- Caregiver persistence
- Social skills training
- Early intervention
- Paying attention to what works for the individual child and following intuition
- Speech therapy, including local dialect/slang, and conversations
- Overcoming sensory issues a little bit at a time
- Charting items like tantrums, sleep patterns, eating patterns, language development, interactions with teachers and parents, etc.
- Communication with school teachers
- Cooperation between parents and teachers
- Adapting teaching styles to learners
- Routine / flexibility with consistency
- Reminders / multiple reminders
- Teaching life skills like bill paying, driving, hygiene, cooking, etc.

RESEARCH QUESTIONS ANSWERED BY THIS STUDY

- 1) What are the interventions that had a positive impact on youth with Asperger's Syndrome?
- 2) What are the behavior patterns that had a positive impact on youth with Asperger's Syndrome?
- 3) What interventions were used or not used that had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?
- 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic environments and adult life?

INTERVENTIONS AND BEHAVIOR PATTERNS WITH A NEGATIVE IMPACT

The difference between the Parent Data and the Student Data in relation to the interventions and behavior patterns that had a negative impact on youth with AS was extreme. The first and most obvious difference was the volume of data. The Parent Data contained only two quotes to answer Research Question 3¹² and no quotes to answer Research Question 4¹³. In contrast, the Student Data contained five quotes to Answer Research Question 3 and 13 quotes to answer Research Question 4. Seven out of the 11 answers to Research Question 5¹⁴ were recommended solutions to interventions and behavior patterns that had a negative impact. Subjects did describe negative experiences, but they were shared in order to help others avoid some of the misery they themselves experienced. Along with the negative experiences, there were numerous positive experiences, interventions and behavior patterns shared.

Parent Data

This contrast tells volumes about the personal burden of living through life with AS. It becomes far more dramatic when combined with the well-documented literature regarding the challenges of parenting a child on the Autistic Spectrum. Raising a child on the Autistic Spectrum has been found to be more exhausting and more challenging than other extreme life challenges like military deployment, bankruptcy, caring for a child with cancer and even the death of a spouse. Divorce rates have been frequently misquoted and embellished, but are documented to be 10-15% higher for parents of Autistic Spectrum children than the national average in the United States and lower marital happiness in Australia (Doheny, 2010; Ghose, 2010; Higgins et al., 2005). Even with the limited sample size of this study, the fact that the Student Data revealed between nine and 12.5 times more answers than the Parent Data to the

¹² 3) What interventions were used or not used that had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?

¹³ 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?

¹⁴ 5) What interventions and/or behavior patterns can be implemented across a broad range of youth with Asperger's Syndrome to better prepare them to succeed in academic environments and adult life?

Research Questions that had a negative impact on youth with AS is startling. The researcher has not found any data describing this difference in current literature. This begs to question how much carry-over this has into adulthood and how much impact this has on adults with AS who are receiving government aid and are unable to live on their own. It also lends credence to the parental plea for early intervention and attention to the individual. It is possible parents sense some of the burden their children carry even though their words did not reveal it in the data. Their words did not articulate this burden or dwell on it, but their desire to intervene and assist their children in navigating through a neurotypical world shows an awareness of it and a desire to protect their children from a burden they likely sense. The CHILD-AUTISM-PARENT-CAFÉ website provides numerous statistics regarding adults and their dependence on their families and other government and other subsidized services in the United Kingdom (<http://www.child-autism-parent-cafe.com/adults-with-autism.html>). Most parents are making every effort while their children are young to prepare them for independence and fully-functioning lives in a neurotypical world.

Student Data

One other stark contrast between the Parent and Student Data: Bullying was not mentioned in the Parent Data. There are seven quotes in the Student Data with direct references to specific incidents of bullying and several others that have more subtle implied inferences. With 25 video monologues included in the study, that means 28% of those included in this study contain specific incidents of bullying. One video (4%) was selected due to an intervention regarding bullying. The others were selected because of the interactions with parents or teachers and bullying was a random topic revealed in the data analysis.

When analyzing the findings for Research Question #4¹⁵ in the Student Data, the bullying by adults, especially teachers, had not been anticipated by the researcher to such a great extent. Much of the literature makes reference to bullying by peers and those with AS

¹⁵ 4) What behavior patterns had a negative impact on youth with Asperger's Syndrome that may have been changed based on current knowledge?

feeling ostracized and alone because of it, but not much is written about bullying by teachers and school staff (Attwood, 2007; Robison, 2007). This begs the question:

- Is this because those in positions of power and respect cover up the bullying?
- Is it because bullied children are not believed by other adults at school?
- Do bullied children believe they will be taken seriously at home?
- Do children believe that caregivers taking action will make things worse?
- Is it because the children have a limited exposure to human interaction and think the bullying is normal?

The researcher believes it is likely a combination of all of the above, with particular emphasis on limited exposure to human interaction. Students with AS often have communication deficits and frequently have less association and verbal interaction with peers than their neurotypical counterparts (Asperger 1944/1991; Wing, 1992). This makes them less likely to converse about bullying situations and likely not to tell their parents or other caregivers about bullying incidents – and less likely to know how common the bullying behavior is. If they are the target of the bullying, it also makes it less likely others will explicitly explain it to them when it happens because many on the sidelines of the bullying incident(s) either join in the tormenting or fear the bully themselves. Those on the sideline may not be aware that the AS victim does not understand many of the social nuances of the bullying rituals, even though they cannot escape the unpleasantness. If the AS victim does not understand that the behavior of the bully is out of the ordinary, they are not likely to tell anyone about it – whether or not it makes them feel miserable. They are caught in a vicious circle perpetuated by their own deficits – and by those most capable of helping them build their skills and awareness and decrease their deficits. This places an added responsibility on caregivers to provide each child with an accurate understanding of what is “normal” in the social settings in which they are most likely to find themselves and to teach them the verbal skills to communicate the goings on in those environments. It also increases the importance of being involved in the day-to-day happenings of the school to enhance parental awareness of any potential problems (Attwood, 2007).

There is evidence in the literature to suggest this bullying will continue into the adult work place (Johnson, 2011; Saperstein, 2010; Simone, 2010). This makes it more important than ever to teach AS children how to recognize bullying and how to handle it appropriately

when they are young. As shown in the behavior patterns that resulted in a positive impact in the lives of AS youth, opposites can also be true. Just as many references were made in both the Student Data and the Parent Data regarding the positive impact of early diagnosis on AS and communication with teachers and others who have an interest in a child's well being, postponing diagnosis and refusing to communicate with others was shown to have a negative impact on youth with AS. There may even be some cases where communicating the AS diagnosis and its associated traits can reduce or eliminate bullying. If teachers or peers understand the brain wiring and gifts associated with AS and see that there is more to the AS individual than quirks and melt-downs or stubbornness, they may see more potential in the student and be more understanding and accommodating (Grandin, 2011; Robison, 2011; Szatmari, 2004).

Perhaps my unhappiness would have been less severe if teachers had explained the other reasons for chronic social failures. When people fail to understand *why* someone is different, they will often deny him or her the "radical" courtesy of *a chance*.

Few teachers prepared me for the rejections that would come crashing down like the moon-manipulated tides. Or the barren durations of hopelessness when I should have practiced staring into the mirror to germinate a sense of self that was not always going to come from my peers.

Rejection is still unbearable as an adult, and I have never stopped asking the same empty questions.

"What did I do?" (Saperstein, 2010, p. 50)

Once a person has a diagnosis, a potential negative behavior pattern is to use the AS diagnosis as an excuse for rude behavior or not stretching to achieve more. Some choose not to develop their own skills or knowledge. In other words, they use AS as a crutch and purposely give up (Grandin & Barron, 2005; Saperstein; 2010).

There are many common AS traits and tendencies that are important to know and consider. It is important not to expect an AS child to become neurotypical, but that does not mean an AS child is stagnant and will not continue to learn. Allowing the AS child to believe he or she cannot learn or accomplish more is disheartening and demoralizing. All people on the Autistic Spectrum need to be aware of the challenges they are likely to face. This will help them be prepared and set realistic expectations. Each AS child should be continually reminded they can learn and develop skills and abilities throughout their lives

(Attwood, 2007; AutismHangout, 2010a; Grandin, 2011; Robison, 2011; Saperstein, 2010; Szatmari, 2004).

Alexa, Subject #23, shared three separate incidents of being judged by appearance rather than by function. Society is riddled with blatant examples of pressure to look a certain way. The findings in this study revealed social stigmas and expectations far more subtle. Though subtle, these findings revealed a significant impact on individual lives. Due to her low Executive Function, Alexa found that a significant amount of her mental energy and prep time was invested into making sure that her conversations were scripted a certain way and delivered at a certain pace, her eye contact was “appropriate,” that she was prepared with enough small talk and so on. This helped her immensely while she was out in public, but it sapped all her energy and exhausted her to the point that she had to go home and take a nap after these minor activities leaving little energy for other important tasks. She was so good at this in high school, no one seemed to notice she did not have a single friend outside of school activities. Her college counselor was even fooled by her appearance and was almost condescending when telling her he didn’t think she would have any trouble in college because she had excellent eye contact, when he actually had no idea what her trigger points or deficits were. Alexa analyzed her own situation and felt her energy would be much better invested in her school work, job skills, and her personal relationships – not the façade of being polite in public and then going home exhausted and alone.

Interventions designed to increase eye contact are generally considered to have a positive impact on youth with AS (Baron-Cohen & Jolliffe, 1997; Klin et al., 2002; Robison, 2007; Wing, 1992). Most of the findings in this study surrounding eye contact are reported as having a positive impact. There was one incredibly powerful video, however, that gave insight into why eye contact was not only avoided, but emotionally painful for Alan, Subject, #13. Alan felt as if he was being raped on a spiritual level. He said he felt like people could see right through his soul and that they would know everything there was to know about him. It was unpleasant, disturbing and hurt spiritually. Alan said that his soul felt disgusting – like people could reach inside him and do terrible things to him. Subsequently, he chose to avoid eye contact – even if it provoked physical punishment. Alan wondered if others on the Autistic Spectrum feel violated in the same way. If so, could this be the reason they have such an aversion to eye contact and find it so difficult and exhausting? Forcing eye contact

on these individuals without therapeutic interventions to address this problem is an intervention with a negative impact. Nowhere in any literature has the researcher seen such a vivid description that resembles Alan's insight into his aversion to eye contact.

Based on the findings in this study, the most negative behavior patterns that will impact youth with AS are those teachers, caregivers and leaders who refuse to respond to the child as an individual with special needs (Bromley et al., 2004; Higgins et al., 2005). The findings were filled with examples of teachers and school administrators who expected the AS individual to become neurotypical and conform to neurotypical expectations (Robison, 2007). This false expectation was damaging to the students' self-esteem, did not enhance learning and created daily frustrations for both the adult leader and the AS youth. Most of these cases also resulted in annoyance with parental involvement in the schools and outward signs of arrogance by school faculty and staff members. There was even evidence of a turf war being valued above the progress of the student(s). Most of these cases resulted in the student(s) changing schools, sometimes more than once, and sub-standard academic performance incongruent with IQ scores. In each of these cases, the best interest of the AS individual was clearly placed far below the comfort level of the ineffective educator involved.

The researcher assumed that the study would reveal deficits in leadership and preparation that might have had a more positive impact if the educator's understanding of AS had been more current and complete. The combined data analysis from Parent and Student Data in this study revealed the following interventions and patterns of behavior that had a negative impact on youth with Asperger's Syndrome:

- Bullying, particularly by teachers
- Expecting an AS child to become neurotypical
- Delaying diagnosis
- Refusing to share the AS diagnosis
- Unnecessarily lowering expectations
- Refusing to adapt teaching methods or activities to the AS student's interests and abilities
- Judging function by appearance rather than skills and abilities

- Pushing team sports beyond a reasonable experiment
- Propagating social stigmas in media

CORRELATION WITH CURRENT LITERATURE

Temple Grandin is a well-known author in the autism and Asperger community. She grew up as an autistic child in the 1950's. Temple was diagnosed with autism in the late 1940's when little was known about autism and almost nothing about it being a spectrum disorder. Those who received the diagnosis commonly received a recommendation to be institutionalized. The medical, educational, and societal expectations for autistic individuals were extraordinarily low. Fortunately for Temple, her mother denied the recommendations of the doctors and decided to run her own experiment to see if Temple could achieve more than the doctors predicted. Her mother took on a daunting task, but as she got to know her daughter as an individual, and not just a diagnosis, she found that in addition to Temple's behavior abnormalities, she had extraordinary gifts and she made continuous progress.

Her mother used all the resources at her disposal and soon found the parameters within which she could challenge Temple without pushing her into sensory overload and severe tantrums. Consistency in behavioral expectations and discipline techniques from house to house in her neighborhood allowed Temple to develop a base set of manners and coping mechanisms. All the parents in her neighborhood expected – and demanded the same behaviors as her mother – and her mother encouraged the neighbors to adhere to the same discipline used in her own home. This consistency in the neighborhood, combined with speech therapy, pre-school and elementary school that were all unusual for their time proved to be the foundation Temple needed to begin fitting into the social environment around her.

Her mother stayed in daily contact with Temple's school teachers and withdrew television privileges for one evening for disruptive behavior in school. This consistency turned out to be highly beneficial – and motivational for Temple. Temple had a nanny who spent hours playing games with her and her sister. This taught her life skills like turn-taking, sharing, graceful losing and graceful winning. She was clever at designing and building things and other children appreciated this when she built play things they could all use. Her mother used her own involvement in community theater to motivate Temple and her younger siblings to participate as well. They brought this experience home and used it with the

neighborhood children to build sets and put on plays as a group. This trait was also helpful when her mother challenged her to go to the lumber yard or hardware store by herself.

Temple developed an intense love of animals after spending a summer on her aunt's horse ranch – and also gained tremendous self-confidence because she was scared to death to go, but went anyway and was successful.

Temple's mother never withdrew creativity and skill building activities as discipline. She viewed them more as therapy activities and found they had a calming effect on tantrums. Television and idle activities were used for punishment instead (Cutler, 2004; Grandin, 1995; Grandin, 2011; Grandin & Baron, 2005).

Mostly due to Temple's mother paying attention to every aspect of her development and how she responded to everything, much like Subject #8 did when charting her own daughter's every move, Temple's mother was able to help Temple prepare for adult life in a way no doctor in the 1950's predicted possible (Cutler, 2004; Grandin & Barron, 2005). Temple showed a keen interest in science and building. She went on to become a college professor, a leader in the field of feedlot design and cattle handling, and became one of the first people on the Autistic Spectrum to develop the communication skills to speak and write about the condition from an insider's perspective. Temple has written many books and articles, speaks at countless conferences and workshops, and sits on advisory boards for multiple autism research foundations. She not only opened the door for others to share, she opened the door for others to hope (Attwood, 2007; AutismHangout, 2010a; Bashe & Kirby, 2005; Cutler, 2004; Grandin, 2011; Robison, 2011; UOregon, 2010).

Temple Grandin's personal experiences were particularly congruent with the findings of this study. This was expected by the researcher due to Temple's influence on the current knowledge of Asperger's Syndrome and autism, responses to therapies, sensory overload, bullying, social interaction, expectations in the workplace, success in careers, use of technology, individualized development and so on. Having read many of Temple's books and seen many of her presentations, the researcher believes there is evidence her mission is being fulfilled by the research finding many of the same coping mechanisms being discovered by individuals in the study at much younger ages than Temple Grandin was when she made the same discoveries. Youth with AS are able to glean from the experience of those who have already lived through the experience and share what they have learned.

Those pioneers like John Elder Robison, Liane Holiday Willey, Shawn Barron and Luke Jackson have helped neurotypicals and their own community see into the lived experience in a way that neurotypical researchers, no matter how skilled, never found possible. This has helped an entire generation on the Autistic Spectrum to adapt to neurotypical environments more easily and at younger ages than those with AS who came before them. Some possible reasons for this important observation are early intervention, teacher and parental awareness, therapies available, and a shift in cultural acceptance. (Note: Temple Grandin believes that the rigid social norms of the 1950's and 1960's were a benefit to her because they created routine and a common set of behavioral expectations wherever she went. Today's "anything goes" social acceptance makes it more difficult for those on the Autistic Spectrum in her opinion (Grandin & Barron, 2005)). Many of the subjects had access to information and the experience to apply it. This helped many of them begin to discover coping mechanisms on their own.

RECOMMENDATIONS FOR PARENTS, TEACHERS AND VOLUNTEER LEADERS

The interventions and patterns of behavior were compared with an understanding of AS reflected in current literature. Commonalities through the lens of the lived experience were used to recommend approaches in working with AS youth primarily in educational and extra-curricular settings, and as a resource for future research. An underlying goal of education and therapeutic interventions is to assist the AS individuals in becoming independent. This independence includes earning a living as an adult. Both the literature and the findings of this study provided a great deal of focus on employment and preparation for work as well as suggestions for school settings.

The data analysis revealed the following recommendations for parents, teacher and volunteer leaders:

- 1) Individualized Adaptation
- 2) Early Intervention
- 3) Avoid Sensory Overload
- 4) Watch for Bullying
- 5) Balance Looks with Function
- 6) Be Patient

- 7) Apply Routines
- 8) Apply Technology
- 9) Teach Life Skills
- 10) Someone with Asperger's Syndrome Will Never Become Neurotypical
- 11) Encourage Life-Long Learning
- 12) Prepare to Find Interesting Work

The number one recommendation resulting from this study: Individualized Adaptation. Take the time to get to know the individual(s) and then adapt the activity to their abilities and interests (Szatmari, 2004). While this may not sound revolutionary and may seem like a common sense approach, the findings revealed a much different story. Data showed that with all the research, education and training available, this is the single most overlooked element with the potentially greatest impact for the least financial investment of anything that can be done to assist youth with AS. Individualized adaptation requires no special training or policy changes. It does require concentration, outside the box thinking, teamwork and clever activities. Do not expect the AS youth to ever become neurotypical. Look for and encourage potential for growth and development. Learning more about AS and comparing notes with other parents, teachers and leaders will also help. Stay calm when frustrated and get clever in your approach.

The second recommendation is: Early Intervention. Early intervention includes diagnosis, appropriate therapies, especially speech therapy, communication with teachers and other influential adults, educating yourself about AS and other related and sometimes overlapping syndromes like ADD, ADHD, Tourettes and Bipolar and may also impact behavior (Grandin, 2011; Perry, 2004).

The third recommendation is to: Avoid Sensory Overload. Push children to stretch their capabilities and experience the world, but always be aware of the limits sensory overload creates. An AS child who appears to be difficult or obstinate may be reacting to sensory overload. Many tantrums can be diffused by removing the child from a chaotic or noisy environment, eating a snack, taking a nap, wearing a different fabric, changing the lighting, eliminating a smell, etc. Watch for patterns. You may need to experiment to find what can diffuse or eliminate a trigger (Bauminger, 2002; Cederlund & Gillberg, 2004; Cutler, 2004; Grandin & Barron, 2005; Nieminen-von Wendt et al., 2004; Robison, 2011;

Rogers & Ozonoff, 2005; Smith Myles et al., 2000; Tammet, 2006; UOregon, 2010). Coaches, Scout leaders, teachers and others who will become caretakers in your absence must be informed of known triggers the AS child is likely to face while in their care.

The fourth recommendation is: Watch for bullying – both from adults and peers. Educate your young person with AS what to watch for, how to behave, what words to use and what to report to you. Help them avoid as much bullying as possible (Attwood, 2007; Grandin, 2011). When bullying is unavoidable, take them seriously and take action.

The fifth recommendation is: Balance looks with function. Using small talk in conversation, using eye contact, speaking at the “proper” pace, and pretending to be interested in things like sports and music that others are interested in can be important to fit in in society. Young people with AS often find this challenging. This study found that as important as it is to look and act the way others expect, it is just as important to function well. Help your young people with AS balance these two competing demands so they can fit in and still have energy left for the other things that are important in their lives (Attwood, 2007; Grandin, 2011; Tammet, 2006; Willey, 1999).

The sixth recommendation is: Be Patient. Look for reasons behind annoying or disruptive behaviors before correcting them. Stimming¹⁶, boredom, overstimulation or not understanding what is expected in a certain situation all demand different levels of supervision and redirection (Szatmari, 2004; Tammet, 2006).

The seventh recommendation is: Apply Routines. There is clear evidence both in the findings of this study and the literature (Frith & Happe, 1994; Jackson, 2002) that indicates those with AS function better with regular schedules, consistent sleep patterns and knowing what to expect throughout their days. Transitions are known to be difficult. Notification before changes in their routines are made will make transitions easier and lessen the emotional upheaval associated with disrupting routines (CETV, 2008; Szatmari, 2004).

The eighth recommendation is: Use Technology. Technology is the easiest way to individualize assistance. There are tools available like the iPad that come with access to applications that provide customization for varied interests and abilities. The iPad has a

¹⁶ Repetitive, self-comforting behaviors that may seem odd to others.

proven record for engagement and self-direction (AutismHangout, 2010c; Bailey, 2011). Other traditional technology tools like electronic calendar reminders, PDAs and text messages work well for organization and management of transitions (CETV, 2008).

The ninth recommendation is: Teach Life Skills. There is clear evidence both in the findings of this study and the literature (Grandin & Barron, 2005; Robison, 2007; Tammet, 2006; Willey, 1999) that many with AS have a more difficult time learning everyday tasks for independent living than most neurotypicals. These skills require a concentrated effort, step-by-step process and practice. Teach AS youth hygiene routine, housekeeping, cooking, laundry, bill paying and money management, driving, basic car maintenance, dating manners, roommate relations and so on (Bashe & Kirby, 2005). These are things you would also teach neurotypical youth, but AS youth require more specifics, more application to the individual and more practice (AutismHangout, 2010a).

The tenth recommendation is: Someone with Asperger's Syndrome Will Never Become Neurotypical (Frith, 2004; Ramachandran, 2011). No matter how much learning takes place and no matter how well a person with AS fits in, they will never become neurotypical. Don't expect that you can discipline them or require them to sign a contract or respond to any manner of bribery to become "normal." Be patient and appreciate their gifts. Allow them to use their power of concentration, their creativity, their "quirks" and the freedom to be different (Robison, 2011; Szatmari, 2004; Tammet, 2006).

The eleventh recommendation is: Encourage Life-Long Learning. While those with AS will never become neurotypical and should be made aware of the realities of challenges they are likely to face, they should be continually encouraged and reminded that they can learn and their brains will continue to develop throughout their lives. Many of their behaviors and social deficits are delays, not permanent exclusions from neurotypical involvement (Grandin, 2011; Robison, 2011).

The twelfth recommendation is: Prepare to Find Interesting Work. No matter what their intelligence level, there is a high propensity for those with AS to struggle with the school system. This makes the lure of a college education or a trade school daunting for some. It is important to help them select education that is appropriate for their abilities and interests that can prepare them with job skills – and then mentor them to see it through to completion. Those with AS tend to be passionate about certain topics and perfectionistic by

nature. If they can apply this passion to a work environment appropriate to their skills and interests, they are likely to be successful especially if they can balance other tasks they may find mundane, but necessary. They need to be aware of sensory overload and social integration issues in the work place and take these into consideration when choosing a job and a career path (AutismHangout, 2010a; Grandin, 2011; Robison, 2011; Simone, 2010). Organizations like Aspiritech may be of assistance for those with the right skill match (AutismHangout, 2010b; Johnson, 2011). These organizations may also become a bigger part of the placement infrastructure in the future.

STRENGTHS OF THE STUDY

The findings of this study are significant in many ways. This study combines the true lived experiences with current literature. Due to the static video monologues, the researcher could not inadvertently influence the Subjects.

The findings revealed stark differences in perspective between parents of AS youth and those with AS. This is important to consider for future research, selecting and designing therapies and creating policies. Insights like Alexa's reality of exerting all her mental energies on social appearance and ending up exhausted and alone should not be ignored. Intimate descriptions like Alan's feeling spiritually raped by direct eye contact is a revelation this study was fortunate to have obtained and should be explored further in future studies. The discovery of bullying by teachers and school administrators was a significant finding that needs to be addressed by educators.

One of the goals of this study was to produce a set of recommendations for parents, teachers and volunteer leaders that would be applicable across a broad range of youth with AS. This study achieved that goal. The findings revealed an intense need to focus on early intervention and speech therapy and individualized adaptation.

The overall design of this study found that there is an active support community who wants to help those with AS avoid misery and they are willing to share their own experiences to achieve this objective. Several studies like this can be combined to shape future education policy decisions.

The researcher would like to encourage others to contribute by participating in this community. His own lived experience and many discussions with others seeking solutions to

daily challenges reveals a potentially significant contribution to this spontaneous “community” that could greatly enhance its usefulness. Those who have contributed thus far are true pioneers from whom much has already been learned.

LIMITATIONS OF THE STUDY

There are three limitations to this study:

- 1) The sample is limited. This study includes 25 Subjects in a population of thousands. The sample is made up of Subjects who willingly filmed themselves and then posted their videos in a public sphere on their own. These 25 Subjects may be more vocal, extraverted or daring than others in the population they represent in this study.
- 2) The data was gathered from video monologues. This method gave the researcher no ability to ask questions and clarify feedback.
- 3) There was no opportunity to intentionally pair children with their parents, therapists and teachers. This pairing would have provided a full spectrum view of the individuals with AS.

SUGGESTIONS FOR FUTURE RESEARCH

Another study should be done using the same methodology with documentaries as the data source. The findings should be compared to see how much the influence of producers and writers changes the outcome. The researcher suspects from his cursory observations that most of the data analysis has been completed and is being presented as “findings” or “conclusions” rather than raw data. This would allow for more of a meta-analysis and a more comprehensive view of specific therapies and the research behind them.

The researcher suggests performing a similar study that pairs Parent Subjects with Student Subjects. This study included one pair. It was insightful to see the difference in perspective. Pairing the students with their own parents or care providers would be useful before basing treatment and policy decisions on the findings. This is done frequently in the documentaries referenced above.

The discovery of bullying by teachers and school administrators was a significant and disturbing finding that deserves further research and attention. Further study regarding bullying, especially by school teachers and administrators should be done. Those educating students with special needs must question why this kind of bullying takes place and if the findings in this study are generalizable. The following questions are beyond the scope of this study, but are worthy of investigation:

- Are parents being told about the bullying – especially when it is being done by an adult in a position of power rather than a peer?
- Would the students be believed and/or taken seriously if parents were told?
- Would the parents act on the information?
- Would the school system act if the parents acted?

Further research involving the use of technology devices is critical to meet the volume of personalization demands in the treatment of AS. Investigation of this magnitude was beyond the scope of this study due to the cost, length of time and the dispersed nature of the subjects to study.

CONCLUSIONS

This phenomenology study was done using video monologues accessed from public video sharing websites in lieu of traditional face-to-face interviews. The purpose of this study was to survey the personal experiences of individuals with Asperger's Syndrome, analyze and combine them to come up with a shared lived experience then to provide recommendations for parents, teachers and volunteer leaders to help young people with Asperger's Syndrome navigate their way through a neurotypical world and be prepared for an independent and fulfilled adult life.

Literature on Asperger's Syndrome was collected, behavior patterns and social interactions of AS individuals reviewed and analyzed to determine the history of the condition, common symptoms, past and current treatments, current support systems available and the outlook for education and work opportunities for those with AS.

This study presented findings that answered Research Questions in accordance with phenomenological traditions. The findings included significant quotes from the subjects to allow them to tell their own story in their own words. The quotes were summarized after each Research Question.

This study supported previous research on AS. Temple Grandin was used as an example to display the correlation between the study findings and the literature because Temple has high functioning autism and is a well renowned author on the subject of AS and autism. This study found that young people with AS are applying coping mechanisms and skills taught in the literature at an earlier age than Temple did. Theoretically, this is helping

the young AS people today avoid misery and blend more easily into the neurotypical life surrounding them, ostensibly due to the continuous research, nurturing environments, access to therapy and access to information.

The strength of this study was capturing the candid thoughts, experiences and advice of those living through Asperger's Syndrome and synthesizing that into useful information for others.

Further research is recommended in regards to bullying and the application of technology devices that were both beyond the scope of this study. More studies sharing the same methodology, but using different data/subject selection and pairing is highly recommended to discover the generalizability of these findings for policy considerations.

It was the researcher's honor to devote such focused and intensive study to a community so deserving of research, attention and assistance in the pursuit of more fulfilling and passion filled lives.

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APPENDIX A

TREATMENT OF DATA

PSYCHOLOGICAL RESEARCH AS THE

PHENOMENOLOGIST VIEWS IT

MODIFIED FROM P. F. COLAIZZI

TREATMENT OF DATA

Psychological Research as the Phenomenologist Views it

Steps for analysis of a phenomenology research study

1. All the subjects' descriptions were read in order to acquire a feeling for them.
2. Significant statements were extracted from each description, phrases and sentences that directly pertain to the investigated phenomenon. Statements were eliminated that contained t
3. he same or nearly the same statements.
4. Meanings were formulated by spelling out the meaning of each significant statement. In this difficult step, the meanings arrived at must not sever the connection with the original description. The formulations discover and bring out those meanings hidden in the various contexts of the phenomenon that are present in the original descriptions.
5. Clusters of themes were organized from the aggregate formulated meanings. This allowed for the emergence of themes common to all the subjects' descriptions.
 - a. These clusters of themes were referred back to the original descriptions in order to validate them. This was done to see if there was anything in the original that was not accounted for in the cluster of themes, and whether the cluster proposed anything which was not in the original. If either of them was true, re-examination was necessary.
 - b. At this point discrepancies may be noted among and/or between the various clusters; some themes may flatly contradict other ones or may appear to be totally unrelated to other ones. The researcher then proceeded with the solid conviction that what was logically inexplicable might be existentially real and valid.
6. An exhaustive description of the phenomenon resulted from the integration of the above results.
7. The exhaustive description of the phenomenon is as unequivocal a statement of the essential structure of the phenomenon as possible.

APPENDIX B

TOPICS EMERGED FROM STUDENT (PERSONAL) DATA

TOPICS EMERGED FROM STUDENT (PERSONAL) DATA (RAW UNEDITED LIST)

The topics listed below emerged from the video transcriptions of those participants with Asperger's Syndrome. This is the order in which the topics evolved.

• Early Education	• Social Interaction
• Parent Involvement	• Academic Achievement
• Early Education	• Social Skills Training
• Bullying by Peers	○ Therapy Sessions
• Parent Involvement	• Friends
• Abuse by Staff	• Therapy Sessions
• Bullying by Staff	• Friends
• Bullying by Teachers	• Eye Contact
• Bullying by Teachers	• Parental Interaction
• Bullying by Teachers	• Negative Intervention
• What to do About Bullying by Teachers	• Teacher Intervention
• Bullying by Teachers	• Eye Contact
• Bullying by Staff	• Speech Therapy
• Parent Involvement	• Dating & Eye Contact
• Education	• Parent Involvement
• Attention	• Communication
• Educational Environment	○ Misunderstandings
• Parent Involvement	• Rude Behavior
• Attention	• Self-Limitation
• College	• Parent Influence
• Parent Involvement	• Diagnosis
• Bullying by Students	• Therapy
	• Parent Involvement

- Looking Normal vs. Function Normal
- Executive Functioning
- Behavior Symptoms
 - Stimming
 - Melt-Downs
 - Annoyance to others
- Self-Esteem
- Family Support
- Patience
- Diagnosis Problems
- Teachers
- Parent Involvement
- Parent Involvement
- Teacher Intervention
- Diagnosis
- Social Skills / Intervention
- Sibling Interaction
 - Siblings Pay a Price
- Good Teachers
- Work
- Aspie Parent
- Advantages of Diagnosis
- Control Mood Swings / Tantrums
- Work
- Work
- Aspie Parent
- Sensory Toleration

**TOPICS EMERGED FROM STUDENT (PERSONAL) DATA
(FILTERED AND CLUSTERED)**

APPENDIX C

TOPICS EMERGED FROM PARENT DATA

TOPICS EMERGED FROM PARENT DATA (RAW UNEDITED LIST)

The topics listed below emerged from the video transcriptions of the parents of those participants with Asperger's Syndrome. This is the order in which the topics evolved.

- Diagnosis Problems
- Advantages of Diagnosis
- Working with Teachers
- Diagnosis
- Behaviors
 - Public Shame
- Speech Therapy
- Good Teachers
 - Know the Kid
 - Become Advocates
- Early Intervention
- Work / Jobs
 - Life Skills
 - Self-Sufficiency
- Social Skills Training
- Therapy
 - Follow-up at Home
- Sharing Information
- Communicate with Teachers
- Fight with Schools
 - Shouldn't Have to, but ...
- Focus on Strengths
 - Self-Esteem
- Work
- Puppet Show
 - Communication Interaction
 - Communication Intervention
 - Follow-up from Therapy
- Diagnosis
- Symptoms
- Behaviors
- Treatment
 - Team Decision & Prioritization
- Support
 - Team Effort
- Teamwork
- Sports
- Routine
- Advance Warning
- Testing Medications
 - Team Unity
- Symptoms
- Learning Style
- Early Intervention
- Social Skills
- Diagnosis

- Strengths
- Trust Instincts
- Speech Therapy
- Sensory Toleration
- Tracking Everything
 - Behavior
 - Data
 - Diet
- Tantrums
- Diet
- ADHD Crossover with PDD /
Autism Spectrum
- Diagnosis
 - Educate Yourself
- Ask Questions
- Parent Has Same Diagnosis
- Using Technology
- Preparing & Reminding
- Team with Teachers
- Teacher Intervention
- Learning Styles
- Adaptations
- Adaptations
- Respect
- Friends
- College – Implied
- Academic Achievement – Implied
- Eye Contact
- Self-Esteem

**TOPICS EMERGED FROM PARENT DATA
(FILTERED AND CLUSTERED)**

APPENDIX D

IPAD APPS AND RESOURCES FOR AUTISM

IPAD APPS & RESOURCES FOR AUTISM AND OTHER SPECIAL NEEDS

Compiled by a parent, an adult with autism and an SLP – Updated Constantly

Shannon Des Roches Rosa writes at: www.thinkingautismguide.com

Corina Becker writes at: autisticapp.blogspot.com and nostereotypeshere.blogspot.com

Jordan Sadler, SLP writes at: www.communicationtherapy.net and communicationtherapy.wordpress.com

Questions or suggestions: shannonrosa@yahoo.com

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Advocacy							
iAdvocate	Strategies, simulations, & resources to build parent advocacy skills & knowledge.	Free	http://itunes.apple.com/us/app/iadvocate/id427814325?mt=8	n/a	http://thinkingautismguide.blogspot.com/2011/06/interview-iadvocates-alan-foley-on.html		6/25/2011
Art							
Art of Glow	Make lovely glowing patterns to play and stare at. Soothing, sensory.	0.99	http://itunes.apple.com/us/app/art-of-glow-pro/id380120815?mt=8	http://itunes.apple.com/us/app/art-of-glow/id387680399?mt=8	http://autisticapp.blogspot.com/2010/09/mood-pad-and-art-of-glow.html		
Chalkboard Pro for iPad	Simple drawing app on "chalkboard" background	0.99	http://itunes.apple.com/us/app/chalkboard-pro-for-ipad/id365964154?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism		
DrawFree	Magnadoodle-like simple drawing	Free	http://itunes.apple.com/us/app/draw-free-for-ipad/id366755447?mt=8	n/a	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		
Draw With Stars	Animated drawing & methodical erasing	0.99	http://itunes.apple.com/us/app/draw-stars-play-musical-animated/id367460661?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://www.youtube.com/watch?v=EKD Y98s-q6g	
FacesiMake	Fun, free-form collage making	1.99	http://itunes.apple.com/us/app/faces-imake-premium/id389101695?mt=8	http://itunes.apple.com/us/app/faces-imake-lite/id357230884?mt=8	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://www.youtube.com/watch?v=39EAF18J1mA	
Books							
Andrew Answers	"Seriously silly," supports language building through word play, repetition, and cheekiness.	2.99	http://itunes.apple.com/us/app/andrew-answers/id406162881?mt=8		http://www.squidalicious.com/2011/02/rainy-day-apps-leo-loves-and-one-mali.html		
A Present for Milo	A cat chases a mouse while incidental animations abound. Words appear automatically and are read out loud.	3.99	http://itunes.apple.com/us/app/a-present-for-milo-a-touch/id405288824?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/20043563	5/7/2011

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Dr. Seuss's ABC	Great Interactivity - click each word to hear, or use autoplay. Supports sight reading.	3.99	http://itunes.apple.com/us/app/dr-seuss-abc/id354855128?mt=8	http://itunes.apple.com/us/app/dr-seuss-abc-lite/id409976618?mt=8	http://www.squidalicious.com/2011/03/dr-seuss-abc-this-is-how-all-apps.html	http://www.youtube.com/watch?v=X4MAVVGxAp8	
Dr. Seuss's Hop on Pop	Great Interactivity - click each word to hear, or use autoplay. Supports sight reading.	3.99	http://itunes.apple.com/us/app/hop-on-pop-dr-seuss/id376079483?mt=8		http://www.squidalicious.com/2011/03/ipad2-weve-seen-we-want-we-wait.html		
Dr. Seuss's Mr. Brown Can Moo	Mr. Brown can make any noise. Click each word to hear, or use autoplay. Supports sight reading.	3.99	http://itunes.apple.com/us/app/mr-brown-can-moo-can-you-dr/id433316002?mt=8&ign-mpt=uo%3D2		http://www.squidalicious.com/2011/05/day-leos-been-waiting-for-mr-brown-can.html		5/3/2011
Little Bella: I Close My Eyes	Silly and lovely animated book. Good for kids with fine motor challenges. Beautifully animated interactive book.	0.99	http://itunes.apple.com/us/app/little-bella-i-close-my-eyes/id304163263?mt=8		http://www.squidalicious.com/2011/03/apps-leo-loves-tallytots-and-little.html	http://www.youtube.com/watch?v=NP1yLVINFg4	
The Fantastic Flying Books of Mr. Morris Lessmore	Delightful to kids and adults! Comes with the story and a video short. Designed by ex-Pixar character designer William Joyce.	4.99	http://itunes.apple.com/us/app/the-fantastic-flying-books/id438052647?mt=8		http://www.mediabistro.com/qalleycat/the-fantastic-flying-books-of-mr-morris-lessmore-soars-to-top-of-book-app-category_b34089		
The Monster at the End of This Book	Lovable, Furry old Grover! Animation/interactivity, dynamic word highlighting	4.99	http://itunes.apple.com/us/app/the-monster-at-end-this-book/id409467802?mt=8		http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html	http://vimeo.com/19372983	
Tacky the Penguin	A penguin who doesn't fit in earns the affections of his group. Different modes support pre-readers & early readers.	2.99	http://itunes.apple.com/us/app/tacky-the-penguin/id407708819?mt=8		http://www.squidalicious.com/2011/05/day-leos-been-waiting-for-mr-brown-can.html	http://vimeo.com/22656064	5/3/2011
The Three Little Pigs	Lushly illustrated & animated, fully interactive version of the classic story	7.99	http://itunes.apple.com/us/app/the-three-little-pigs-nosy/id418543664?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/22721416	5/7/2011
Tractor Mac Arrives	A hardworking horse gets replaced by a tractor. Dynamic word highlighting. Interactive, rhythmic story about a boy who just can't stop! Comes with a game that targets facial expression identification.	1.99	http://itunes.apple.com/us/app/tractor-mac-arrives/id412663808?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/22853937	5/7/2011
Zanny - Born to Run		2.99	http://itunes.apple.com/us/app/zanny-born-to-run/id409817073?mt=8		http://www.padgadget.com/2011/01/01/zany-born-to-run-a-book-for-kids-on-the-autism-spectrum/	http://vimeo.com/19110327	
Communication							
GraceApp	Simple picture exchange system developed by & for non-verbal people	37.99	http://itunes.apple.com/us/app/grace-picture-exchange-		http://thinkingautismguide.blogspot.com/2010/11/grace-needed-aac-app-so-her-mom-	http://vimeo.com/19548525	

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
iComm	Picture and voice communication aid for children	Free	for/id360574688?mt=8 http://itunes.apple.com/us/app/comm/id351726761?mt=8	n/a	created.html http://www.blogher.com/personal-stories-behind-awesome-apps-kids-special-needs		
iCommunicate for iPad	An AAC app: create icons with custom text, audio, and voice-over, incorporate them into storyboards	49.99	http://itunes.apple.com/us/app/icommunicate-for-ipad/id364186415?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://vimeo.com/19507864	
NeoPaul	Natural-sounding text to speech (male voice)	Free	http://itunes.apple.com/us/app/neopaul/id334254353?mt=8	n/a	http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html		
ProloQuo2go	Full-featured augmentative & alternative communication solution for people who have difficulty speaking	189.99	http://itunes.apple.com/us/app/proloquo2go/id308368164?mt=8		http://specialchildren.about.com/u/reviews/youradviceneeded/reviewanapp/Proloquo2Go.htm		
SoundingBoard	User-friendly app for creation of individualized picture communication boards (1-9 pics per page) with natural voice recording.	49.99	http://itunes.apple.com/us/app/soundingboard/id390532167?mt=8	n/a	http://news.softpedia.com/news/SoundingBoard-Comes-to-iOS-Gives-People-with-Disabilities-a-Voice-157795.shtml		
TalkAssist	Alternative speech aid; provides a voice through text-to-speech software	Free	http://itunes.apple.com/us/app/talk-assist/id329338159?mt=8	n/a	http://autisticapp.blogspot.com/2011/05/talk-assist.html		5/29/2011
Tap Speak Button	Record messages, use switch-function button to play them back	14.99	http://itunes.apple.com/us/app/tapspeak-button/id359998293?mt=8		http://autism.typepad.com/autism/2010/09/working-the-ipad-stories2learn-and-tapspeakbutton.html		
Earliest Learning							
SoundTouch	Touch cartoons of animals, vehicles, etc. to see real-life photos & sounds	2.99	http://itunes.apple.com/us/app/sound-touch/id348094440?mt=8	http://itunes.apple.com/us/app/sound-touch-lite/id363705863?mt=8	http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html	http://vimeo.com/19111997	
File Sharing							
DropBox Games	Cloud-based real-time file sharing b/t computer & iPad (for worksheets, etc.)	Free	http://itunes.apple.com/us/app/dropbox/id327630330?mt=8	n/a	http://www.squidalicious.com/2011/07/making-reusable-ipad-worksheets-leos.html		7/7/2011
Angry Birds	Experiment with slingshot trajectories, using birds to take out pigs.	0.99	http://itunes.apple.com/us/app/angry-birds/id343200656?mt=8		http://www.blogher.com/10-fantastic-ipad-apps-kids-autism		
Fruit Ninja	Because our kids deserve to play! Fun, very simple swipe-based interface	4.99	http://itunes.apple.com/nz/app/fruit-ninja-hd/id370066032?mt=8	http://itunes.apple.com/nz/app/fruit-ninja-hd-lite/id406247161?mt=8	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Fruit Memory	Concentration, turn taking. Multi- or single player, choose number of tiles. Fun, cute!	0.99	http://itunes.apple.com/us/app/fruit-memory-hd/id379561503?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		
Leaf Jam	Open-ended musical playground. Tap the screen to make the leaves fall.	0.99	http://itunes.apple.com/us/app/leaf-jam/id398410006?mt=8		http://www.squidalicious.com/2011/02/leos-overstuffed-ipad-and-more-apps-we.html	http://www.youtube.com/watch?v=Fr74lSQbunA	
My Underwear	Play with your underwear! Several activities: Paint it, catch it, change it!	2.99	http://itunes.apple.com/us/app/my-underwear/id412488390?mt=8		http://www.squidalicious.com/2011/02/rainy-day-apps-leo-loves-and-one-mali.html		
Poke Me	Play, poke, feed, & guide a cute purple monster in several environments	Free	http://itunes.apple.com/us/app/poke-me-hd/id375492868?mt=8	n/a	http://www.squidalicious.com/2011/06/poke-me-yet-another-app-leo-loves-and.html		6/12/2011
Scoops	Catch the falling ice cream scoops on your cone.	Free	http://itunes.apple.com/us/app/scoops-ice-cream-fun-for-everyone/id291591378?mt=8	n/a	http://momswithapps.com/2010/08/04/characteristics-of-great-apps-for-kids-with-autism/		
Spot the Dot	Find a colored dot in increasingly complicated visual fields. Encourages bystander commentary.	3.99	http://itunes.apple.com/us/app/spot-the-dot/id436198140?mt=8		http://www.squidalicious.com/2011/07/spot-dot-fantastic-social-joint.html		7/24/2011
Toca Tea Party	Play tea party! Set up, serve, and clean up.	2.99	http://itunes.apple.com/us/app/toca-tea-party/id424174500?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html		5/29/2011
General Development							
Injini: Childhood Development Game Suite	Expert-developed, extensive meaningful play suite for children with cognitive, language, and fine motor delays.	49.99	http://itunes.apple.com/us/app/injini-childhood-development/id452962000?mt=8		http://a4cwsn.com/2011/08/injini-childhood-development-game-suite/	http://vimeo.com/28179955	9/7/2011
Geography							
US Puzzle Map	Click-and-drag states into place; state names said out loud for non-readers.	2.99	http://itunes.apple.com/us/app/united-states-puzzle-map/id377699597?mt=8		http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html		
Stack the Countries	Learn about the countries of the world via shape-matching and a stacking game. Non-readers will need support.	1.99	http://itunes.apple.com/us/app/stack-the-countries/id407838198?mt=8&ign-mpt=uo%3D4	http://itunes.apple.com/us/app/stack-the-countries-lite/id407838751?mt=8	http://www.smartappsforkids.com/2011/04/stack-the-countries.html		9/7/2011
Stack the States	Learn 50 US states trivia via shape-matching and a stacking game. Non-readers will need support. Fun.	0.99	http://itunes.apple.com/us/app/stack-the-states/id381342267?mt=8	http://itunes.apple.com/us/app/stack-the-states-lite/id390058619?	http://www.squidalicious.com/2010/12/mali-likes-apps-to-heres-her-top-ten.html		

App	Function	Price	iTunes Link	Lite (Free) mt=8	Review	Video	Added
History							
BrainPop Featured Movie	New animated movie about science or history, every day. With quiz afterward.	Free	http://itunes.apple.com/us/app/brainpop-featured-movie/id364894352?mt=8	n/a	http://www.squidalicious.com/2011/09/india-loves-apps-too-toca-boca-hair.html		9/4/2011
Presidents vs Aliens	Learn U.S. Presidential History facts and faces, with alien battle interludes	0.99	http://itunes.apple.com/us/app/presidents-vs.-aliens/id427418941?mt=8		http://www.squidalicious.com/2011/09/india-loves-apps-too-toca-boca-hair.html	http://www.youtube.com/watch?v=R_BgwcTBOT4&feature=related	9/4/2011
Labeling & Identifying							
ABA Flashcards	A suite of free flashcard apps for identifying labels, from Actions to Zoo animals. From Kindergarten.com	Free	http://itunes.apple.com/us/app/aba-flash-cards-actions/id342235464?mt=8	n/a	http://www.squidalicious.com/2011/03/ipad2-weve-seen-we-want-we-wait.html		
All About Me	Store & practice learning personal information. Useful for those challenged by giving personal information verbally.	0.99	http://itunes.apple.com/us/app/all-about-me-by-i-get-it-llc/id426201106?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html		5/28/2011
Word SLAPs Language	Create & identify 1, 2, or 3 audio-labeled photo icons (instantly, with an iPad2). SLP-created. Excellent for discrete trials.	2.99	http://itunes.apple.com/us/app/word-slapps/id413888079?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/19280701	5/28/2011
Conversation Builder	Pragmatics: Discriminate between subtle differences which can negatively or positively impact a conversation.	5.99	http://itunes.apple.com/us/app/conversationbuilder/id413939366?mt=8		http://a4cwsn.com/2011/04/conversation-builder/	http://vimeo.com/22193488	5/30/2011
Milo: Interactive Storybook	Build language skills by listening to Milo's story, or recording your own version.	1.99	http://itunes.apple.com/us/app/speech-milo-interactive-storybook/id447014224?mt=8		http://www.squidalicious.com/2011/07/developing-apps-that-avoid-special.html		7/25/2011
Question Builder	Learn to answer abstract questions and create responses based on inference. For readers.	3.99	http://itunes.apple.com/us/app/question-builder/id360577727?mt=8		http://www.blogger.com/personal-stories-behind-awesome-apps-kids-special-needs		
Sentence Builder	Learn how to build grammatically correct sentences. For readers.	3.99	http://itunes.apple.com/us/app/sentence-builder/id344378741?mt=8		http://www.blogger.com/personal-stories-behind-awesome-apps-kids-special-needs	http://vimeo.com/18803477	
Speech With Milo: Prepositions	Learn prepositions through animated examples and text reinforcement	1.99	http://itunes.apple.com/us/app/speech-milo-prepositions/id417190136?mt=8		http://www.squidalicious.com/2011/02/rainy-day-apps-leo-loves-and-one-mali.html		

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Speech With Milo: Verbs	Learn verbs through animated examples and text reinforcement	2.99	http://itunes.apple.com/us/app/speech-with-milo-verbs/id405441288?mt=8		http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html	http://a4cwsn.com/?p=1740	
Story Builder	1) Improve paragraph formation; 2) Improve integration of ideas; and 3) Improve higher level abstractions by inference. For readers.	3.99	http://itunes.apple.com/us/app/story-builder/id377631532?mt=8		http://www.blogger.com/personal-stories-behind-awesome-apps-kids-special-needs	http://vimeo.com/18730387	
That's Silly	Absurd pictures entertain young kids while building language & cognitive skills.	0.99	http://itunes.apple.com/us/app/thats-silly/id438876208?mt=8		http://www.squidalicious.com/2011/07/developing-apps-that-avoid-special.html		7/25/2011
Math and Pre-Math							
Arthmaroo	Counting: associating numbers with amounts	1.99	http://itunes.apple.com/us/app/arithmaroo-1-a-counting-math/id353711794?mt=8		http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html		
Count TV	Sesame Street's The Count introduces videos about the numbers 1 through 9	2.99	http://itunes.apple.com/us/app/count-tv/id369229779?mt=8		http://www.squidalicious.com/2011/02/leos-overstuffed-ipad-and-more-apps-we.html		
Dot to Dot Number Whiz	Counting in sequence	1.99	http://itunes.apple.com/us/app/dottodot-number-whiz/id333188500?mt=8	http://itunes.apple.com/us/app/dottodot-number-whiz-lite/id333210438?mt=8	http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html	http://www.youtube.com/watch?v=4i1zuiCqIHE	
Rosita's Jump Count	Shake the iPad to count Rosita's jumps - in English and Spanish	1.99	http://itunes.apple.com/us/app/rositas-jump-count/id365339302?mt=8		http://www.blogger.com/ipad-nearmiracle-my-son-autism		
Silly Numbers	1:1 correspondence and counting numbers 1 - 12, great design & interactivity	3.99	http://itunes.apple.com/us/app/silly-numbers/id370623941?mt=8		http://www.squidalicious.com/2011/02/rainy-day-apps-leo-loves-and-one-mali.html	http://www.youtube.com/watch?v=ngKWlzeB7Ts	
Splish Splash Inn	Counting in English, Spanish, & French	0.99	http://itunes.apple.com/us/app/splish-splash-inn/id391514246?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism		
TallyTots	Counting 1 - 20 through various activities. Motivating, well-designed, easy to use.	1.99	http://itunes.apple.com/co/app/tallytots/id424070269?mt=8		http://www.squidalicious.com/2011/03/apps-leo-loves-tallytots-and-little.html	http://www.youtube.com/watch?v=D9rUyVvpCM	
Whizzit 1-2-3	Practice 1:1 correspondence/counting, with fun balloon-popping breaks	0.99	http://itunes.apple.com/us/app/whizzit-123/id323246993?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://vimeo.com/19277590	
Multiple Activities							
Fish School	Letters, numbers, shapes, colors, matching, and more. Leo-approved.	1.99	http://itunes.apple.com/us/app/fish-school-hd-by-		http://a4cwsn.com/?p=578	http://vimeo.com/19156647	9/7/2011

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Monkey Preschool Lunchbox	Concentration, matching, sorting, color identification, first-letter correspondence	0.99	duck-duck/id367567922?mt=8 http://itunes.apple.com/us/app/monkey-preschool-lunchbox/id328205875?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism	http://vimeo.com/19224393	
Thomas Game Pack	Thomas the Tank Engine & his friends. Matching games, puzzles and mazes.	2.99	http://itunes.apple.com/us/app/thomas-game-pack/id352660283?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism		
Zoo Train Music	Matching, puzzles, spelling, music, and make-your-own trains. Engaging.	1.99	http://itunes.apple.com/us/app/zoo-train/id407870968?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/20729157	5/29/2011
Dropophone	Free-form play with a field of raindrops that cycle in various tones.	Free	http://itunes.apple.com/ee/app/dropophone/id376771022?mt=8	n/a	http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html		5/28/2011
Hand Drums	Drums are a logical step for the touch-based iPad interface. Big, realistic-looking drums.	0.99	http://itunes.apple.com/us/app/hand-drum/id380564151?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism		
Itsy Bitsy Spider	Interact with a much-loved children's song via fun animations & verse repetition	0.99	http://itunes.apple.com/us/app/id331863487?mt=8		http://www.squidalicious.com/2011/02/rainy-day-apps-leo-loves-and-one-mali.html	http://www.youtube.com/watch?v=XlqXsZ_Zsow	
Moozart	Play, explore, and experiment with favorite songs, & the basics of music reading.	1.99	http://itunes.apple.com/us/app/moozart/id405194870?mt=8		http://www.squidalicious.com/2011/02/leos-overstuffed-ipad-and-more-apps-we.html		
PianoBall	Using spinning balls to change a keyboard's features & do musical free play.	1.99	http://itunes.apple.com/us/app/pianoball-fun-with-learning/id431494130?mt=8		http://www.squidalicious.com/2011/08/leo-loves-music-apps-pianoball.html	http://www.youtube.com/watch?v=gJ0_yFYJ-Q4	8/29/2011
Singing Fingers	Finger paint with sound!	Free	http://itunes.apple.com/us/app/singing-fingers/id381015280?mt=8	n/a	http://www.squidalicious.com/2011/07/singing-fingers-app-for-free-form-music.html		7/31/2011
Songify	Turns spoken words into music (dance tracks, etc.) Motivating!	Free	http://itunes.apple.com/us/app/songify/id438735719?mt=8	n/a	http://www.squidalicious.com/2011/07/ipad-workshops-drama-and-songsmithing.html		7/13/2011
Tappy Tunes	Tap out favorite songs in the rhythm of your choosing	1.99	http://itunes.apple.com/us/app/tappytunes/id299495181?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism		
Toddler Sing & Learn	Puzzle, color, and sing along with eight favorite songs.	1.99	http://itunes.apple.com/us/app/toddler-sing-learn/id421465168?mt=8		http://www.squidalicious.com/2011/04/app-review-kiboomus-toddler-sing-learn.html		

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Twinkle Twinkle Storybook Piano Navigation	Learn to play songs by following the colored keys on a keyboard	0.99	http://itunes.apple.com/us/app/twinkle-twinkle-little-star/id375672904?mt=8		http://momswithapps.com/2010/08/04/characteristics-of-great-apps-for-kids-with-autism/		
FastMall Productivity	navigate any mall map without the need for GPS or WIFI.	Free	http://itunes.apple.com/us/app/fastmall-shopping-malls-community/id340656157?mt=8	n/a	http://autisticapp.blogspot.com/2011/01/fastmall-app.html		
Epic Win	Streamlined to-do list, with a role-playing spin.	2.99	http://itunes.apple.com/us/app/epicwin/id372927221?mt=8		http://autisticapp.blogspot.com/2011/02/epicwin.html		
iEarnedThat	A puzzle-based reward system that uses custom images	1.99	http://itunes.apple.com/us/app/iearnedthat/id366144564?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		
iReward Puzzles	Fun, interactive reward tracking system. Can also use as a token board.	4.99	http://itunes.apple.com/us/app/ireward/id324643198?mt=8		http://www.asparenting.com/2011/02/09/ireward-app-review/	http://vimeo.com/19492514	
My First Tangrams	An adaptation for kids of the famous Tangram game.	1.99	http://itunes.apple.com/us/app/my-first-tangrams-hd/id363843653?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism	http://www.youtube.com/watch?v=ik19lnxtE9I	
ShapeBuilder	An errorless click-and-drag puzzle game, reinforces sight reading	0.99	http://itunes.apple.com/us/app/shape-builder-preschool-learning/id306572986?mt=8	http://itunes.apple.com/us/app/shape-builder-lite-the-preschool/id310642448?mt=8	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		
US Puzzle Map Reading & Spelling	Click-and-drag states into place; state names said out loud for non-readers.	2.99	http://itunes.apple.com/us/app/united-states-puzzle-map/id377699597?mt=8		http://www.squidalicious.com/2011/01/ipads-slps-perspective-including-more.html		
BOB Books #1: Reading Magic	Build and read sentences through drag-letters-into-place word building and animated picture prompts.	1.99	http://itunes.apple.com/us/app/bob-books-1-reading-magic/id403753501?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism	http://vimeo.com/19688877	
FirstWords Deluxe	Drag tiles to spell words in an error-free environment, reading	4.99	http://itunes.apple.com/app/firstwords-deluxe/id337462979?mt=8	http://itunes.apple.com/us/app/firstwords-sampler/id312571156?mt=8	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://www.youtube.com/watch?v=m9U9U1cPi64	
Mr. Thorne Does	Extensive video phonics	7.99	http://itunes.apple.com/us/		http://www.squidalicious.com/		5/28/2011

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Phonics - Letters and Sounds	demonstrations for early readers (note: British spellings)		app/mr-thorne-does-phonics-letters/id431679830?mt=8		2011/05/oodles-and-oodles-of-apps-leo-likes.html		
Word Magic	Sight word-based spelling and reading via fill-in-the-blank letters.	0.99	http://itunes.apple.com/us/app/word-magic/id293630633?mt=8		http://www.blogger.com/10-fantastic-ipad-apps-kids-autism	http://vimeo.com/17512145	
Word Wagon Science	Drag letters to spell words in a playful Paris scene. Uses sight reading & phonics.	1.99	http://itunes.apple.com/us/app/word-wagon-by-duck-duck-moose/id423629048?mt=8		http://www.squidalicious.com/2011/05/oodles-and-oodles-of-apps-leo-likes.html	http://vimeo.com/21426281	5/28/2011
BrainPop Featured Movie Self-Care	New animated movie about science or history, every day. With quiz afterward.	Free	http://itunes.apple.com/us/app/brainpop-featured-movie/id364894352?mt=8	n/a	http://www.squidalicious.com/2011/09/india-loves-apps-too-locaboca-hair.html		9/4/2011
iDress for Weather Social Skills	Pick appropriate clothes for current weather conditions. For individuals with disabilities, an educational tool for children, or just for fun.	1.99	http://itunes.apple.com/us/app/idress-for-weather/id385227220?mt=8		http://teachingall.blogspot.com/2011/01/appmondaytas-idress-for-weather.html	http://vimeo.com/18520397	
Look in My Eyes	Motivate your child to look people in the eyes	2.99	http://itunes.apple.com/us/app/look-in-my-eyes-1-restaurant/id349835339?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		
QuickCues Social Media	Social scripts that help people on the autism spectrum handle new situations & learn new skills	4.99	http://itunes.apple.com/us/app/quickcues/id360381130?mt=8		http://slpsharing.com/2010/06/17/quickcues/		
FlipBoard Social Stories	Read Twitter, Facebook, and RSS feeds in less-overwhelming magazine layout	Free	http://itunes.apple.com/us/app/flipboard/id358801284?mt=8		http://appchronicles.com/12/flipboard-review-media-evolving/	http://creativity-online.com/work/flipboard-flipboard/20728	5/6/2011
ModelMe Kids: Going Places	Helping learn to navigate challenging community locations through slide shows of children modeling appropriate behavior.	Free	http://itunes.apple.com/us/app/model-me-going-places/id347813439?mt=8		http://www.lunchboxreviews.com/app/model-me-going-places		
Stories2Learn	Create custom social stories, using your own photos, text, and voiceover	13.99	http://itunes.apple.com/us/app/stories2learn/id348576875?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://www.youtube.com/watch?v=uvoC3eyFZK4	

App	Function	Price	iTunes Link	Lite (Free)	Review	Video	Added
Speech							
ArtikPiks	Practice sounds targeted in speech therapy with flashcards, memory games. Pictures are line drawings. Child can record own voice and listen. Buy for \$29.99 loaded with sounds or free and add sounds as child is ready.	29.99 / Free	http://itunes.apple.com/us/app/artikpix-full/id356720379?mt=8	http://itunes.apple.com/us/app/artikpix/id383022107?mt=8	http://specialchildren.about.com/u/reviews/youradviceneede/reviewanapp/ArtikPix.htm	http://vimeo.com/18647719	
Articulate It	Track data for many students at once, with option to email data, notes, and even child's recorded voice to parents and other team members. Therapist has option to target specific phonemes, phonological processes, or modes of articulation. Target words are real photos.	49.99	http://itunes.apple.com/us/app/articulate-it/id391296844?mt=8		http://www.geekslp.com/2011/02/articulation-carry-over-and-the-ipad/		
Visual Schedules							
First Then Visual Schedule	Create digital visual schedules with several format options	9.99	http://itunes.apple.com/app/first-then-visual-schedule/id355527801?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://vimeo.com/19644485	
Writing and Fine Motor							
iWriteWords	Guided handwriting with a really fun, reinforcing interface	2.99	http://itunes.apple.com/app/iwritewords-handwriting-game/id307025309?mt=8	http://itunes.apple.com/us/app/iwrite-words-lite/id308152258?mt=8	http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html	http://www.youtube.com/watch?v=8ZTkPtAygOY	
Penultimate	Free-form writing/drawing app with lined/graph paper options & notebook functionality for storage. Great with stylus.	1.99	http://itunes.apple.com/us/app/penultimate/id354098826?mt=8		http://www.squidalicious.com/2011/05/leos-penultimate-stylus-for-ipad.html		5/30/2011
SuperNova	Practicing pinch-and-expand motions	0.99	http://itunes.apple.com/us/app/supernova/id375160139?mt=8		http://www.squidalicious.com/2010/11/leos-ipad-apps-for-kids-with-autism.html		

Apps Resources			
Apps for Children With Special Needs (Scores of Video Demonstrations)	www.a4cwsn.com		
Apps in Education	http://appsineducation.blogspot.com/		6/4/2011
IEAR: iEducation Apps Review	http://www.iear.org/		
GeekSLP: Apps for SLPs	http://www.scribd.com/doc/49125628/iPad-iPhone-iPod-Android-Apps-for-Speech-Therapists		

GeekSLP: Top 5 Apps for Spanish Speech Therapy	www.geekslp.com/2011/01/apps-for-bilingual-slps-and-english-speaking-speech-therapists-working-with-spanish-speaking-children/	
iPhone/iPad AAC Apps: Spectronics Inclusive Learning Technologies	http://www.spectronicsinoz.com/article/iphoneipad-apps-for-aac	
iPodsibilities: Apps and Autism	www.ipodsibilities.com/iPodsibilities/AppsAndAutism.html	
Jeremy Brown's App Recommendations for Kids With Autism	www.scribd.com/doc/47441495/Jeremy-Brown%E2%80%99s-App-Recommendations-for-Students-with-Autism	
Speech-Language Pathology Sharing (heavy on AAC and iDevices)	slpsharing.com	
There's a Special App for That	http://www.inov8-ed.com/category/special-app-for-that/	6/4/2011
iPad Resources - Research & Education		7/7/2011
Autistic children use iPad at Toronto school to reach out and communicate	http://www.google.com/hostednews/canadianpress/article/ALeqM5gCraXNupq-zCMCWZSJ4mgqtRjosw?docId=6886416	5/20/2011
Helping autistic children with iOS devices	http://www.tuaw.com/2010/08/18/helping-autistic-children-with-ios-devices/	
iAutism.info: List of Academic Papers on iPads and Autism	http://www.iautism.info/en/2011/04/09/links-to-academic-papers/	
iPad Academy	http://ipadacademy.com/category/collections-compilations	
iPads4Education	http://ipads4education.ning.com	
iPad Curriculum	http://www.ipadcurriculum.com	
iPads for Learning - 21 steps to 1:1 success	http://asp-uk.secure-zone.net/v2/index.jsp?id=639/684/1625&utm_source=ipadsummary	
iPads in the Classroom Paper.li (daily article roundup)	http://paper.li/MathEvolve/1309107859	7/7/2011
iPods, iPhones, & iPads in Education	http://ipodsiphonesineducation.wikispaces.com/	
Learning: Is there an app for that?: Cynthia Chiong & Carly Shuler	http://www.joanganzcooneycenter.org/Reports-27.html	
Mobile Devices and Autism: Autism News of Orange County [PDF]	http://www.autismnewsoc.org/docs/AutismNewsWinter11.pdf	
Moms With Apps: Teachers Discuss iDevices in the Classroom	http://momswithapps.com/2010/12/21/teachers-part-ii/	
Preparing Your School for an iPad Implementation	http://ht.ly/1dwk2v	7/7/2011
SETT Framework for AAC evaluations	http://edweb.tusd.k12.az.us/assistive_technology/AT_SETT.htm	
iPad Accessories - Cases, Styluses, etc.		
Drawing on the iPad: 12 touchscreen styluses reviewed	http://www.macworld.com/article/156560/2011/05/touchscreen_stylus_roundup.html	5/7/2011