

## Autism Spectrum Disorder: A Case Study Presented from a Parent's Perspective

**Thaddaeus C Dachille**

Doctoral Candidate, Curriculum and Instruction  
Indiana University of Pennsylvania  
1011 South Dr, Indiana, PA 15705, USA.

### Abstract

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*This paper presents two case study style observations that were conducted by a parent of a seven-year-old child living with High-Functioning Autism Spectrum Disorder (HFASD). The case study operates as a needs assessment to understand the particular interaction limitations facing the child. These observations also attempt to illustrate the noticeable behaviors that parents, friends, relatives, and caregivers may notice in children on the spectrum. Information in this paper will also provide some guidance and reassurance that these behaviors are not exclusive to only your child. In the discussion, the paper provides some specific elements found in all of the observations which highlight the Autistic behavior that is manifesting in interactions with others. A graphic organizer presented in the findings highlight the particular nuances of Autistic behavior identified by the child's father.*

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**Keywords:** Autism awareness, High-Functioning Autism Spectrum Disorder (HFASD), parent and child relationships

### Introduction: I'm lucky to be a father

As parents, teachers, caregivers, and other adults who love a child on the spectrum we want what's best for them in life. We know that they are slightly different from their peers and that's also what doctors and other practitioners tell us. Being honest, children on the spectrum do at times exhibit noticeably different behavior from other kids their age. Therefore, to help our children with ASD achieve better success in life, we as parents and caregivers need to better understand the specific needs of the child or children we are caring for. This objective directed me as a parent to conduct a needs assessment of my child to better understand his strengths and limitations. The first step in this process, I felt, was to identify my own bias. This is a continual process. In other words, I must reiteratively and intentionally recognize the subjective lens that prevents me from seeing my unique child from a completely outside perspective. This is important to me because behavior modification of noticeably awkward manners need to be addressed now (before my child is older and has become set in his ways).

Moreover, studying my child firsthand gives me the understanding that life can be especially hard if you act differently from your peers. Furthermore, I find it important to know the specific challenges that my child finds to be very hard to complete. But, before I speak about the specifics of my own child, I want to first address some very general overlapping themes that people on the ASD spectrum have difficulty with like, social relations (American Psychiatric Association, 2013). And, like this example from the American Psychiatric Association, as a parent, I too have noticed some socially awkward behaviors, in regards to socialization. Like when my son was showing a friend how to ride a bike but, the other boy was already a proficient rider. Being the sweet and loving child that I know he is, he pushed him repeatedly while the child was adamantly saying, "No, no!" Honestly, at the time he was providing verbal communication telling him how to balance the bike in conjunction with the physical pushing. In this example, my son was trying to help his friend yet, he couldn't decode the other boy's communication. I share this in the front matter of this paper because it provides a glimpse of the kind-hearted nature of my child. Also, this illustration provides an indication of the challenge of daily interaction faced by many children on the spectrum.

From my preliminary understanding of my child, like other children with Autism, he sees the world in a different but beautiful way. From a perspective provided by his pediatrician, my child needs more modeled behavior than his peers to help illustrate what manners he should use in daily life. The doctor went on to say he is like a blank slate, literally, a “tabula rasa.” With this state of being, he needs meaningful social guidance in public situations as to help him act appropriately, to lead him towards his autonomous future, a future that will not always include my parental scaffolding. Most importantly, I have heard from many professionals and other parents that this diagnosis of ASD is not a one-way ticket to a bleak future and helping my child grow into an autonomous, successful adult, is accomplishable.

### **Identifying my own bias**

As the father of the participant in this case study, I have to note an obvious bias. Yet, to attempt to remove partiality, as a researcher, I consciously tried to write down the direct experiences as they happened. I felt that by working carefully to detail what was occurring in the observations, I was more likely to think about the behaviors and the experiences rather than to overtly express partiality in the writing process. During the observations, I interacted with him as a participant yet, attempted to remain emotionally distant during the encounters (as to also write down the observations accurately). Regretfully, I did not inform him that he was being actively researched. My rationalization for not telling him about the research was twofold. First, he is very young and I am not sure that he would completely understand what I am doing. Secondly, my wife and I have never officially sat down and explained to him that he has Autism and what that implies.

### **Literature review: Seeing autism from a bigger picture**

Autism has a long history. It was first written about in scholarly format in 1943, by Leo Kanner, who also gave a name to the phenomena (Kerrell, 2010). Apparently, Kanner chose the word Autism because it comes from the Greek word meaning “autos” which describes the “self” and this connected with Kanner’s participants because they were all apparently socially withdrawn (Kerrell, 2010). Nowadays, ASD is now more widely recognized and professional acknowledgment of the continuum is common. Moreover, diagnosing the phenomena is also very streamlined. Generally, to diagnose a child on the spectrum, a professional assessor must notice at least three observable criteria of ASD in a setting (Boslaugh, 2008). It is important to note that although the diagnosis criteria are very standardized, there are many behavioral nuances of people on the spectrum. Like the common behaviors of my child which include being extremely outgoing, loving, kind, and enjoying the occasional use of his blanket when he is stimming (which basically means that his senses are overloaded). And my son shows difficulty modeling appropriate physical proximity with other people - among other traits. For others on the spectrum, their particular behavioral distinctions would be different, like being extremely withdrawn and non-social. It is also important to stress that no two people on the spectrum are the exactly the same. Nevertheless, there are some transferable themes that I will try to illustrate over the following paragraphs beginning with the work of Ellen Notbohm.

In, *Ten things every child with autism wishes you knew*, the author explains how she raised her son, Brice, to be an autonomous, independent adult with ASD. In the book, Notbohm explains that her son has had many successes including graduating high school and completing a landmark journey of traveling across the United States by himself (Notbohm, 2005). But, Brice’s journey and Ellen’s parenting expedition hasn’t always been easy. For instance, there were examples in her book of family trips that had to be cut short because Brice was overwhelmed by the sensory experiences in a new environment (Notbohm, 2005). But, to make the journey of Autism easier for others in Notbohm has developed a comprehensive list of the 10 things that all parents, caregivers, and teachers should know about their autistic children – as to better tailor life-skills to each child’s specific needs. Essentially, Notbohm’s list includes but is not limited to many common themes in ASD such as sensory integration, excessive meltdowns, visual learning preference, echolalia (the repeating of noises, sounds, and phrases), and concrete thinking. Again, these specific aspects are very typical of children on the spectrum but, incredibly helpful as every caregiver should at least know about some of these items on Notbohm’s list!

Like Notbohm, other parents and caregivers have also expressed difficulty communicating with their child on the spectrum. Similarly, having your child understand other people’s emotions can be equally challenging. I myself am very familiar with stating and restating to my son, “It’s time for bed!” In instances like this, he does not seem to absorb what I am saying. What appears to be happening, in these all too common bedtime scenarios is he is not understanding emotionally where I am coming from. Like this example, all 10 parents who participated in a qualitative descriptive research study experienced a similar occurrence.

In the study, designed to attempt to define the challenges and familiarities of families in their communication with their Autistic child, all of the parent participants mentioned that they too have problems with “receptive and expressive language domains of communication” when interacting with their child (Alli, Abdoola, Mupawose, 2015, p. 82). Essentially, you have to spell out for your child explicitly your needs and your expectations are because they will most likely not be able to infer from your tone of voice or the situation the demands that you are expecting from them.

Another aspect, presumably found in most individuals on the spectrum includes the need to be given a multiverse of experiences in order to thrive (Kerrell, 2010; Kangas, Uusiautti, Määttä, 2011). There is an inability in areas, which include, “difficulty with planning alternative outcomes, problem-solving, and imagining what will happen next” (Kerrell, 2010, p. 3). And so to develop well-versed adults, children with ASD need to be around supportive individuals who are willing to model how to both start an interaction with a peer and affably end an interaction (Kangas, Uusiautti, Määttä, 2011). To instruct children on the spectrum caregivers need to be trying different forms of communication to find what works best for your child. For instance, some children with ASD are more visual and it may be helpful to provide “visual prompts (photos, objects of reference) to prepare the child” for a required direction or task (Plimley, Bowen, Morgan, 2007, p. 5). Like varied experiences, children on the spectrum also respond to full parental involvement. In fact, just like mothers, fathers play an important role in the well-being of children with ASD. In a study conducted in India, fathers participated in a number of sessions to learn how to engage and teach their children on the spectrum how to play. The researchers noticed tremendous gains in the children’s “engagement and understanding of play” (Louis and Kumar, 2015, p. 114). Moreover, this research provides an understanding that there are many benefits to paternal involvement with Autistic children that include but are not limited to “functional use of language both receptive and expressive skills” (Louis and Kumar, 2015, p. 119). Again, all children are different but, this transferable advice for parents and caregivers can be helpful in positioning any child with ASD for future and current success.

### **Theoretical framework: Constructing an understanding of ASD together**

For this project, the theory of constructivism was used. The rationale for using this theory included the consideration that doing research on my child constructs a reality of him through observation. Similarly, he is co-constructing life-tools from his experimentation with communication in various real-life situations. In conjunction with this statement, I believe in the notion that his growth is synchronized with daily advancement, where he is refining his tools of communication with “communal experience” (Comstock, 2013, p. 2). Much like how earlier civilizations gave way to more refined technologies that better produce lasting memories with newer tools, these experiences are mnemonic-like, memory producing and enduring (Comstock, 2013). Moreover, the observations were taken in situations that are “individually oriented” to the needs of the participant (Prawat, 2008, p. 2). Also, one of the founders of the theory, Leo Vygotsky, postulated that over time the more knowledgeable other (or me) would progressively give the “control” of steering decisions and interacting skillfully, “to the novice as he or she becomes more skillful in implementing the practice” of operating in public settings (Prawat, 2008, p.)

### **Methodology**

Ultimately, this study was conducted to better understand my son. And the research was generated in an effort to produce an understanding of his strengths and weaknesses in regards to interactions in community spaces. As his father, I understand that his behaviors are unique to him and our family but, not always exclusive to other children on the spectrum. To record the observations and produce the field notes I used both a notebook and an iPhone 6. The rationale for using a case study format included the desire to provide a transparent example of day-to-day life situations using a journal-like format (Houghton, Casey, Shaw, Murphy, 2013). Additionally, to keep my child’s name anonymous, I generated a pseudonym.

### **Case study one: At the park**

*This observation takes place at the park, the approximate observation time 60 minutes. The majority of the time Samuel was playing in the sandbox by himself, presumably enjoying the texture. Over the course of the hour, two interactions with different younger children occurred in this setting.*

Samuel was quietly playing in the sandbox at the park by himself. The park is a quiet setting, populated at the time with about 10 other children playing nearby on swings and slides. The time was about 6 pm and long shadows were cast over the sandbox and the other park amenities by large trees. The park is nicely developed with modern equipment, large growth trees, and boulder-sized rocks integrated into the setting.

Samuel was approached by a child, who was nonverbal, he appeared to be around 2.5 years old. They quickly began playing together. Samuel had a paper cup and he was using it as a mold to make sand forms. He said to the other child, “No, you pick up sand like this. So, you don’t get the light brown stuff get the dark brown stuff.” He wanted the other child to use the top layer of moist sand to make stronger molds. His lecture went on for about five minutes according to my iPhone. Then he looked up at me and said, “Daddy I have someone here to help me.” Then, he immediately went back into scolding the other child saying, “No, not the light brown the dark brown.”

Then the child went over to another spot in the sandbox to play. Samuel stood up and kneeled next to the other child to show him how to play. The other child was using a large plastic sand mold that was left in the sandbox. Samuel showed him how to scoop with his hands gathering large amounts of sand (like a cat in a litter box). Then a few minutes later the child left the sandbox.

Later, another child came over to the sandbox. His father was standing next to him and when I asked him he said the child was 16 months old. The father prefaced the interaction between Samuel and the toddler by saying, “he doesn’t understand words yet.” Samuel quickly drew a large line around his sand bucket castle. When the child crossed the line, he put his hand on his foot attempting to trip the child, and the child almost fell. Although I was taking notes, I interrupted the interaction and scolded Samuel for trying to trip the young boy. Then, he moved his hand to his waist to try and prevent the child from knocking over his sand form. This protective behavior continued until the child and the father left the sandbox area a few minutes later. It was clear that he was hyper-passionate about his construction yet, he lacked the verbal communication needed to express this. Moreover, in the observation, he showed a desire to teach, to guide, to build and his passion for creative hands-on experiences.

### **Case study two: The football game**

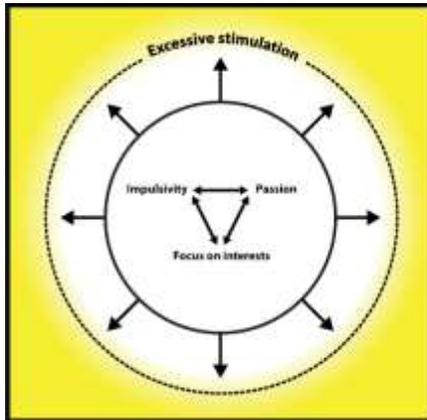
*This observation takes place primarily in a football stadium. The approximate observation time was 180 minutes.*

We drove to the college football venue, walked to the front gate and entered the stadium (we were a little late and arrived during half time). Samuel was very excited when we handed him his ticket (it was a golden ticket Willy Wonka-like situation for him). Upon entering the elevator and arriving in the booth, it was a box seat, Samuel sprang into action moving quickly around the entire room, jumping up and down, eating food, and he covered the entire square footage of the room within minutes of his arrival. Then, he calmed down a bit and sat next to his grandfather. But, nevertheless, he was clearly overwhelmed by the thousands of people in the stadium, the hard-hitting football action, seeing two large TV screens simultaneously along with a small screen in the box room, seeing his grandparents, and the other people in the room he began stimming. My dad (and probably me as well) hovered over him to calm him down. My father has a technique that works very well with him, he squeezes his arm periodically, and this helps calm him. Luckily, we arrived very late and missed most of the game, so Samuel was not as incredibly overwhelmed as he would have been had we arrived earlier at the game.

Later on, when I was tucking him into bed, I asked him what he thought of the event. He was unable to give complete sentences, but instead, he offered parts of the memory along with other fragments from other experiences perhaps found on television. He said, basically, there was an underground football stadium with machines that launch dirt wads and lightning into the air.

### **Discussion**

From these observations, specifically, I have identified several themes in the data that evidenced themselves with his interpersonal and intrapersonal communications. Foremost, my son shows impulsivity, in fact, he seems to be unaware of the custom of waiting for one's turn. This is something that as a family we have been aware of. However, relooking at the impulsivity he showcased, particularly in the first case study, provided me with a new understanding that this could be seen as a strength. Impulsivity is related to risk-taking, which is a key factor needed in the 21<sup>st</sup> century for success along with independence and self-management (Warner, 2006). And if this behavior were applied to our society, this mindset could be used to cure cancer, facilitate interplanetary space travel, and ultimately advance society. Also, identified in the observations was the information that he shows little regard for other people’s personal space coupled with an intrinsic desire to help other people. In regards to his lack of interpersonal personal space, it indicates that I need to work on teaching him how to make a more pronounced effort to use eye contact. But, this is a not a critical problem as research indicates that children with ASD, that can provide eye contact, prefer larger interpersonal distances once eye contact is established (Asada, Tojo, Osanai, Saito, Hasegawa, & Kumagaya, 2016).



Three “positive” attributes discovered in the observations included impulsivity, passion, and focus. “Positive” was used to describe these characteristics because they can be harnessed appropriately for a successful adulthood. Realistically, with ASD, there is a surrounding zone that extends into each interaction known as “Excessive stimulation.” This was described as an expanding zone which implies that he can be greatly affected by situational stimulation that varies depending on the novelty of an environment. Personal space was not identified in this graphic because research indicates that with training personal space can be decreased (Asada, Tojo, Osanai, Saito, Hasegawa, & Kumagaya, 2016).

In a more general sense, through these observations, I have learned firsthand as a parent that observing your child on the spectrum and watching how they assess the changing pace of life and interact in various situations is incredibly important. As, unlike other children that can infer or abstract communication and behavior, thereby acting differently in new and different social situations children with ASD cannot. Therefore, children on the spectrum need as many experiences and understandings as possible to manifest the appropriately modeled behavior in a new and different situation (Kangas, Uusiautti, Määttä, 2011). Basically, really trying to be a student of your child gives you, as a parent, caregiver or teacher, a diagnostic tool to better understand their unique communication needs. As a parent, I have also learned that children on the spectrum do not deviate that much from other neurotypical children, in that all children respond to sensory experiences and can express love and concern towards others. However, I will say, it is apparent that when a child on the spectrum is doing something sensory oriented they generally have a deep sense of hyper-focus, or at least my son does, than in other non-sensory situations. I also learned a great deal about my parenting. I discovered that I need to be less instantaneous about scolding my child in the heat of an interaction among peers. I need to remain calm and quietly remind him, in a private setting, where and how he can make his interactions with others more suitable socially. Foremost, I need to stop apologizing for his behaviors to others and let him learn to take ownership of his actions.

### Conclusion

The thing about my son that makes him so special, to me, is every time his behaviors are out of control and he has had numerous meltdowns he often does something tremendously special. For instance, he likes to give my wife flowers or just run up to me and hug me. Instances like this have provided me with the understanding of just how lucky I am to be his dad. Moreover, from these experiences, I have learned that children with ASD are just as warm and caring as their peers but, they have more “personality.” Here, I hope that it is obvious that I am redirecting the baggage-like construct of having a disability. Instead, I am placing the child/person/individual/adult and his or her actions over the stigma-placing, distance-causing, and learned-helplessness giving implications of having a disability.

Learning about your child on the spectrum is important. Knowing your child will help him or her, now and in the future, no matter what nuances they have or if they are on or off the spectrum. Importantly, I must not let the behaviors and meltdowns trespass on the love that I have for my child. I have seen this occur many times in my short experience with being a parent. Also, I try and let go of identifying my son as an “Autistic” kid and instead simply see him as my son. This is a difficult task and I hope that by writing this I am being proactive in this endeavor. Honestly, I still find myself thinking negative thoughts (that he will have a bleak future) that simply exemplify the effort that I need to put forth as a parent to provide him with the quality parenting he deserves. And I hope that this transparency that I am writing with is not just me being a “jerk” or a “bad parent.” Instead, I hope that these thoughts are critical to the formation of true emotional qualities that many successful parents must manifest to raise a child on the spectrum.

In closing, the title “Autistic” can be burdensome and can potentially cause internal negative feelings such as resentment or opposition towards your child. Therefore, I am considering dropping the use of any title when describing a child with ASD – unless it is medically necessary. In fact, one physician said this about the title of ASD, “labels could be misleading and unhelpful” (Solomon, Holland, Middleton, 2012, p. 10). More so, I think that labels can evidence themselves as guilt and I think this feeling can become very persistent in many families.

This guilt is a fog that detracts from daily life and can prevent impactful parenting and teaching from occurring. Also, this blame-like thinking fuels the feeling that more precautionary behavior could have done to prevent the “disability.” Perhaps the culpability is also associated with the thought that more can be done now, in day-to-day life that can “heal” the child. Through this writing, I have learned that I need to put less emphasis on the characteristics of the spectrum and more importance on seeing my child as my special, beautiful son – to help him. Personally, I have a lot of work to do. With this information, I also learned that I need to stop apologizing to others for his behavior. I learned that I need to start seeing him in the now and appreciating him today for who he is. Perhaps we, as a society, can redefine the stigma of “disability” through awareness to begin to emphasize only the positive attributes. Thus, working on myself is a critical first step in this revision process.

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