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# A Day in a Life of Autism

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A Day in a Life of Autism

A thesis submitted to  
Regis College  
The Honors Program  
In partial fulfillment of the requirements  
for Graduation with Honors

by

Hailey Benesch

May 2016

**A Day in a Life of Autism**  
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## Preface

This is essentially a review of autism and how it is integrated into society.

## Acknowledgments

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## Introduction



That smiling guy is my older brother, Tyler and he's the main reason why for the past year I have been intensively studying autism. He is 25 years-old, nonverbal, and while society deems him as "special needs", our family just thinks he is just pretty special. As you can see, Tyler is generally a happy guy, but he also has his fair share of difficulties. Yet after multiple doctors visits our family was never really told why he has all his difficulties or why he is "special needs". That was until about a year ago when a doctor finally gave us a one worded answer, Autism. Initially, it seemed so simple, until we quickly realized that even though we had been living with someone with autism for several years, we had no clue what it was. Therefore, shortly after his diagnosis I used this opportunity to gain a better understanding of Tyler and why he is the way he is and delved into the world of autism. And this is what I found.

## Chapter 1: What is Autism?

The word *autism* was originally crafted in 1912 by a psychiatrist to explain a characteristic society thought was part of childhood schizophrenia (Solomon, 2012). Essentially, the word was used to describe a state when a child seemed disconnected from reality and their actions were illogical (Pennington, 2009). It wasn't until 1943, when an Austrian psychiatrist named Leo Kanner first used the word *autism* instead to identify a new specific disorder (Solomon, 2012; Pennington, 2009). In his paper titled *Autistic Disturbances of Affective Contact*, Leo Kanner described a group of 11 children who had a constellation of symptoms that no other diagnosis could encapsulate (Kanner, 193). He identified several behaviors that we today find synonymous with autism including the need for sameness, preference for isolation, and language/communication abnormalities (Kanner, 1943). Only a year later, a pediatrician named Hans Asperger also released a paper, whose focus was on a group of adolescents who had very similar symptoms to Leo Kanner's initial autism patients except that they were more verbal and seemed higher functioning (Pennington, 2009; Solomon, 2012). Now to clarify, people with autism didn't just start popping up in the 1940s. There are some historical accounts that describe individuals with the characteristics of autism, indicating that people with autism have probably existed for centuries (Donvan, & Zucker, 2016). For some reason though in the 1940s their existence was finally being noticed.

While Leo Kanner and Hans Asperger both discussed similar symptomologies at similar times, their resemblances stopped there. Asperger's Syndrome became the fruit of Hans Asperger's work and for a time was used to describe a higher functioning form of

autism (Pennington, 2009; Solomon, 2012). Apart from their difference in diagnostic names both scientists also had differing etiological theories for autism. Has Asperger was convinced that genetics was the root of autism while Leo Kanner theorized that the disorder was psychological in origin (Kanner, 1943; Pennington, 2009; Solomon, 2012). Unfortunately, Kanner was more famous and recognized than Asperger, so the view of the psychological origin spread and became popularized, which resulted in the autism population becoming institutionalized or shoved away into asylums (Donvan, & Zucker, 2016). It wasn't until 1964 when researcher Bernard Rimland, a parent of a child with autism, supported Asperger's claim and suggested that autism was caused by something biological, not psychological (Pennington, 2009; Solomon, 2012). The biological view persisted and has lead to the research heavily involved in the biological causes of autism (Pennington, 2009). While the transition of reasoning has created better understanding of the disorder there is still a large information gap involved with autism both for the public and scientific communities (Solomon, 2012).

For example, even after 73 years of research and exploration, we still do not know what causes autism. While autism is 90% genetic, researchers can only identify a few causal genes to explain the etiology of autism for 15% of its population (Amihăesei, & Stefanachi, 2013). The rest of the genes that researchers have tied to autism are only risk genes (Amihăesei, & Stefanachi, 2013). Additionally, while most researchers would agree that there is some neurological or biological alteration that causes autism, few can agree on what it is, resulting in several different causal theories for autism. Yet even with all of these varied theories, there is still no conclusive evidence for any of them (Williams

et al., 2014). Some researchers believe that something in the environment may be causing autism. This is certainly tempting to consider when looking at its rates. When autism was first recognized as a distinctive disorder, it was reported that about every 4 in 10,000 people were diagnosed with it (Williams et al., 2014; Pennington, 2009). Today, the rates have skyrocketed to alarming numbers as high as 1 in 68 (Bhat, Acharya, Adeli, Bairy, & Adeli, 2014; Data and Statistics, 2015, Solomon, 2012). Because of this 147-fold increase in the rates of autism, some researchers believe that an environmental factor is causing autism. Overall though, there is no conclusive evidence in what it is or how to prevent it (Blaxil, 2004; Williams et al., 2014; Pennington, 2009). Some scientists identify that these rates have changed solely because the diagnostic measures for autism have improved, broadened, and changed since the 1970's, which would lead to more people being diagnosed and hence the increased rates (Wing & Potter, 2002).

This discrepancy in the scientific field about what causes autism only hints at the complexity and difficulty surrounding autism. Autism in its own right is a complicated disorder that researchers and clinicians have a hard time identifying. Even within recent years the American Psychiatric Association has altered its description and qualification of autism again in its newest addition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013). Also autism is often difficult to understand and identify because its spectrum holds a vast array of people. On one end of the spectrum one can have social disinhibitions yet are able to maintain themselves in society. On the other end of the spectrum one can have no verbal or social ability and rely completely on a caretaker (Solomon, 2012). Yet despite the unknowns of autism and its large range and

complexity, autism can and does have specific diagnostic criteria that people can become acquainted with. According to the DSM-5, which became effective in August of 2015, Autism Spectrum Disorder (ASD) is identified by two broad categories, deficits in social/communicational aspects and rigid, repetitive behaviors (DSM-5, 2013).

For the social/communicational aspects of autism the DSM-5 has three subcategories (DSM-5, 2013). The first subset includes “deficits in social-emotional reciprocity” (DSM-5, 2013). For example, several people with autism are uncomfortable with initiating or maintaining conversations (Solomon, 2012) while others honestly don’t understand how to have a conversation (Pennington, 2009). A clinical example is of a nine-year-old boy with autism named Sam. He was found to be highly intelligent, had an IQ of 125, yet when asked a question he would respond and then proceed to talk about whatever interested him, at the time it was Star Wars. He would not ask other people questions or show interest in having a conversation with them (Pennington, 2009). While part of this social problem was attributed to his hyper focus, another deficit associated with autism, it was also related to his lack of understanding or desire to have a reciprocal conversation (DSM-5, 2013; Pennington, 2009). Additionally, considering almost half of autism population are unable to or rarely use speech, its easy to see why communication is difficult for them (Pennington, 2009).

People with autism also seem to lack interest in interacting with others (DSM-5, 2013). Often this becomes clearly present in preschool or elementary school when the child is seen choosing to be alone or denying interactions with other children. Parents will also notice that when a child is interested or excited about something, the child will

not bother to acquire the parents' attention to share in their enjoyment (Pennington, 2009). Some find this inability or lack of interest in interactions with others troubling. Many psychologists believe that human interaction is crucial for personal development (Pennington, 2009). Therefore, some theorize that if a child isolates themselves in early childhood, they may be unconsciously impeding on their ability to develop and therefore make their autism more prominent as they grow chronologically older (Pennington, 2009). For parents, this lack of forming relationships can also be upsetting or frustrating because they feel as if their child doesn't love them, no matter what they do (Solomon, 2012). Betsy, a mother of a child with severe autism claimed that "Even when she's snuggling with you, it can be just because she needs some deep-pressure input. Not 'Oh I love you,' but 'It's warm; I can push against it.' I don't know if she recognizes me" (Solomon, 2012). She recognizes that even her child's physical interactions may not be for love or an attempt at an emotional interaction, but instead an action to fill a sensory need.

The second subset of the social/communication aspect of autism includes "deficits in nonverbal communicative behaviors used for social interaction" (DSM-5, 2013). One example of this deficit is a lack of understanding of emotional cues, like facial expressions, body positions, or how to reciprocate them. Highly functioning people with autism often admit they had to learn how to make certain facial expressions. For example, Temple Grandin, a highly functioning person with autism that is a professor, designer, and author claims that her mind works "like an internet search" and that she stores pictures to provide "more templates...of how to act in a new situation" (Solomon,

2012). Essentially people with autism who are more socially aware often have to learn how to respond to emotional situations to be able to function in society. They don't have the innate response that most people have. For those who have less practice or are less socially aware, they may respond inappropriately to certain emotional cues. For example, someone may be upset and instead of developing a sad expression, they laugh (Pennington, 2009). Several people with no understanding may consider this mean or heartless, when in reality the individual with autism does not know how to respond to the emotional situation. Some people with autism rarely even smile because of their deficits in showing or understanding emotion. (DSM-5, 2013).

A third nonverbal deficit a child with autism may lack is the ability or understanding of looking someone in the eyes (DSM-5). While some may identify this deficit as trivial, it is not. Several psychological studies have shown that people consider eye contact as a good indicator of intelligence (Wheeler, Baron, Michell, & Ginsburg, 1979). This could be a disadvantage for higher functioning people with autism that have higher IQs, especially in scenarios such as interviews or interactions with teachers and peers. Also some higher functioning people with autism state that it is almost shameful for them that they cannot maintain eye contact (Solomon, 2012). John Elder Robison, an individual who wrote about his experience as a person with autism in his autobiography *Look Me in the Eye*, claims that while he didn't understand the concept of looking someone in the eye he "felt ashamed, because people expected [him] to do it" (Solomon, 2012). For those who are socially aware enough to know that their social conduct is considered abnormal to society, a reaction such as John Robison's is typical.

In fact, higher functioning people with autism are often more depressed because they are aware of how their social abnormalities are a disability to them in society and prevents them from interacting (Solomon, 2012).

The third subset of the social/communication aspect of autism includes a difficulty in creating or keeping friendships (DSM-5, 2013). This is caused by a variety of factors. As previously stated people with autism often have little drive to share interactions or emotions with individuals (Pennington, 2009). If one does not have a drive to have interactions or share emotions, it is often difficult to cultivate friendships. Also as previously mentioned, people with autism have a difficult time responding to or understanding emotions (Pennington, 2009). Without prior knowledge, people may perceive their lack of emotional understanding as rude or unwelcoming. Therefore, an a person with autism, because of lack of understanding, might find it difficult to make friends because of their social deficits. The DSM-5 also states that people with autism often become stuck in a pattern or way of acting and often cannot alter their behavior (DSM-5, 2013). Their inflexible behavior may be inappropriate or undesirable in certain situations making it difficult to cultivate and keep friendships that often vary or change based on context (DSM-5 2013). Finally, several people with autism also have speech deficits or entirely lack speech. This deficit in basic communication can make it difficult to make friends let alone keep them. Overall, there are several reasons why individuals with autism may find it difficult to interact in society and cultivate relationships.

The second broad category of autism, rigid, repetitive behaviors, also has several sub categories. The first sub category according to the DSM-5 is “repetitive motor

movements, use of objects, or speech” (DSM-5, 2013). Repetitive motor behaviors include behaviors such as hand flapping, clapping, rocking, and so on (DSM-5, 2013; Solomon, 2012). From personal experience it is clear that the repetitive motor behaviors are extremely prevalent when individuals with autism are excited or in distress. My brother Tyler will flap his hands whenever he is happy to see someone, excited by the prospect of going somewhere or upset when he is denied something or misunderstood. Tyler will also make repetitive noises too, often humming or moaning, but this is often used as a calming mechanism for himself. Several think that these idiosyncratic behaviors are only prevalent in low functioning people with autism but several high functioning people with autism have admitted on autistics.org that they “flap, finger-flick, rock, twist, rub, clap, bounce, squeal, hum, scream, hiss and tic” (Solomon, 2012 p. 283). They too are subject to even the physical oddities of autism.

The second subset of the category of repetitive behavior is the “insistence on sameness, inflexible adherence to routines or ritualized patterns” (DSM-5, 2013). Often people with autism will want to keep their environments and patterns the same. This means they want their surroundings, like their room, their house and so on to have the same organization and appearance. If something in their environment changes or alters, the individual may become upset or angry. While this is an innate characteristic of autism some suggest this characteristic could be driven by their sensory sensitivity (Solomon, 2012). Often people with autism can be super sensitive to light, sound, colors, touch and many other things (DSM-5, 2013). Therefore, they may try to keep their environment consistent so they are not exposed to new sensory disturbances, which can often be an

overload for them (Solomon, 2012). Along with maintained and consistent environments, people with autism are often insist upon regular routines or patterns of behavior and will become upset if these routines are broken as well (DSM-5, 2013; Solomon, 2012). For example, some individuals have very strict eating schedules and can only eat certain things during certain times. If each meal does not meet a certain requirement, they often can no longer eat for the rest of the day (Pennington, 2009). These rigid routines make it difficult for the individual and their families to experience change. Life changes such as the introduction or progression of school, new family members, or moving could be extremely upsetting to an individual with autism.

The third subset of the category of repetitive behavior is centered around “highly restricted, fixated interests that are abnormal in intensity or focus” (DSM-5, 2013). These fixations are no mere hobby or passion. They become so intense that often the individual will only want materials relating to their interest and may only speak about their interests for long periods of time. These hyper focuses can interfere with task completion that is often necessary in family constructs, schools and society in general. The clinical example of Sam previously mentioned also had a highly restricted fixation of Star Wars. He would want no other books or toys relating to space travel, he only wanted things associated with Star Wars. In conversation it was difficult to get him to talk about anything but Star Wars as well (Pennington, 2009). One can imagine how such an intense focus might be aversive to other peers and further exemplify why its hard for people with autism to interact. Most people will only listen to a topic for so long before they become tired, bored, frustrated or annoyed.

Overall, one can see that while there are two categories used to define autism, the categories have many subsets with several symptoms. Also the two categories present a range of symptoms demonstrating how one could have slight or severe autism. Yet even with all of the possibilities of symptoms and ranges, the DSM-5 does clarify that one must meet strict qualifiers in order to be diagnosed with autism. For example, they must meet all three subsets of the first category and meet standards of the second category to be considered as having autism (DSM-5, 2013). Also one can only have autism if these symptoms were developing/occurring during early childhood (DSM-5, 2013). For low functioning people with autism the symptoms are usually prevalent enough to make an early diagnosis from the age of 1 to 3. For higher functioning people with autism the symptoms may not be as prevalent or prevalent until the ages of 5 or later (Pennington, 2009). In order for a child to be diagnosed with autism, the symptoms additionally need to cause significant inhibitions in their life and their symptoms cannot be explained by any other prognosis or issue (DSM-5, 2013).

The DSM-5 also clarifies that autism and its symptoms should be classified in three levels of severity as well. Level 1 is considered the lowest severity of autism (DSM-5, 2013). While the individual can communicate coherently they often need social support in order to thrive. Without it, they would have reduced capability of forming connections and may struggle with reciprocal conversation (DSM-5, 2013). Also their repetitive patterns and inflexible behavior could impede social interactions and be disruptive enough to cause unassisted living to be difficult (DSM-5, 2013). Level 2 is considered the second highest level of severity (DSM-5, 2013). The individual will need

much more support than level one to be able to function in life. Their breadth of speech may be limited and they may have deficits in all types of communication in general. Even with support they may not be able to maintain interactions with other people as well (DSM-5, 2013). Their repetitive behaviors would also be noticeable enough to the common observer and change would cause great distress (DSM-5, 2013). Level 3 is considered the highest severity level of autism. The individual's ability to communicate is severely impaired to where they may be confined to a few phrases if any words at all (DSM-5, 2013). Their social interactions are extremely limited and only used to attain basic needs. This individual would also need the most support out of all the three levels and would not be able to live independently (DSM-5, 2013). Their routines and repetitive behaviors are often so ingrained any type of disturbance could cause extreme distress (DSM-5, 2013).

As one can see, a day in a life of autism is confusing and challenging. For an individual with autism, they have to face a vast array of difficulties each day. For the professionals who also encounter and work with autism everyday must also be a challenge. They have to navigate through the several different presentations, phenotypes and severities of autism and try to make sense of it all. So one has to wonder when considering autism, what could possibly cause such a vast array of symptoms that affect such a large number of people?

## Chapter 2: What Causes Autism?

The answer to the question from the previous chapter is that we are not sure what causes the constellation of symptoms that we call autism. However today, the theories of etiology are at least more diversified and realistic than when autism was in its infancy years of discovery.

Before autism was even given a name, society often associated its traits with either being divinely inspired, produced by insanity, or just motivated by pure oddity (Donvan, & Zucker, 2016). In 1943 though, when parents were finally given a label for what produced their child's odd and rare behavior, they wanted to know what caused it. The initial explanation, as describe earlier, was that autism was psychological in origin. At first glance this explanation may seem innocent, when in reality it was grossly wrong and harmful. It was devised in an age when psychoanalysis and Freudian theory were rampant (Donvan, & Zucker, 2016). Therefore, a blame game was quickly developed to determine who or what caused the psychological disruption that caused autism. Mothers unfortunately won the unlucky draw as being identified as the causers (Donvan, & Zucker, 2016).

Who caused autism was actually first proposed by an article in *Time* magazine (Medicine: Frosted Children, 1948). In 1948, they released an article that described parents of children with autism as "cold" toward their children and because of the parents' personality, their children were "kept neatly in a refrigerator which didn't defrost" (Medicine: Frosted Children, 1948) The article was essentially claiming that parents of children with autism were shutting out their kids, and robbing them of

desperately needed love and attention. Therefore, the parents were intentionally keeping them in an emotionally “freezing” environment. This environment is what caused their children to introvert into themselves and acquire the core characteristics of autism. From this one article the term “refrigerator parents” was born (Donvan, & Zucker, 2016). Quickly though, the fathers were somehow absolved from the responsibility while the mothers took all the blame. This concept became more ingrained into society when Leo Kanner supported this reasoning in (Kanner, 1943). While Leo Kanner had the reputation of defending parents with autism, he also would note in his papers how the parents had distasteful qualities themselves like being obsessed, cold, and removed (Kanner, 1943). Even the foremost authority on autism was claiming that parents of children with autism were the cause and to blame. As a result of his standing in the autism field, several other prominent figures agreed with his position. One such authority, Dr. Bruno Bettelheim, went so far as to say that “when children had autism, it was because their mothers wanted them dead” (Donvan, & Zucker, 2016). Mothers, who were already taxed with the challenging responsibility of raising their child with autism, became additionally shunned and berated by society for doing such terrible things to their children. Confused and desolated themselves, the mothers scrambled to enroll their children with autism into any type of program that would “cure” their child, while they themselves went to therapy to try and figure out what they could have done that was horrible enough to cause their child’s autism (Donvan, & Zucker, 2016).

With little evidence for the claims, by the late 1960s to early 1970s researchers and parents were beginning to question what a mother could possibly do to cause their

child's autism (Donvan, & Zucker, 2016). People started to realize that there was little to no evidence substantiating this “refrigerator mother” hypothesis and that often mothers of children with autism were as much if not more loving and devoted to their children than other parents. Researchers and psychologists started finally using the scientific method to see if the hypothesis could be substantiated and found that it could not. The researchers could not even find a correlation Mothers who were identified as sweet and caring would have both children with autism and “normal” children. Others who were described as cold though had no children with autism (Donvan, & Zucker, 2016). The lack of causality or even evidence that parenting was what caused autism was finally brought to light. As this theory was expunged, a new theory was needed to replace it. A British researcher named Andrew Wakefield thought he found it in 1998.

In the late 1990s, Wakefield had a number of case studies who were diagnosed with autism. Several also had the common complication of gastrointestinal issues (Wakefield et al., 1998) He noted though that the parents were claiming that both the autism and the stomach issues had coincided with a specific event, the child's MMR (measles, mumps and rubella) vaccination. He published this correlation in a prominent medical journal of Britain called *The Lancet* and soon society was in an uproar (Gerber, & Offit, 2009; Wakefield et al., 1998). While vaccinations were widely used and quite common at this point, they were still relatively new. Therefore, both doctors and pharmaceutical companies were clamoring to support their safety, while parents were increasingly wary (Donvan, & Zucker, 2016). Wakefield only stoked the fire by claiming that the vaccine's safety was “A moral issue for [him]” indicating that anyone who

refused to investigate the vaccine's safety was immoral and wrong (Donvan, & Zucker, 2016). Wakefield originally hypothesized that the MMR vaccine could cause autism because the immune system of a child could not handle the three vaccinations at once and hence caused complications (Wakefield et al., 1998). Other theories began to crop up saying it was not just the MMR vaccine but all vaccines because they contained mercury, a known toxin to the neurological system. Regardless of the why, vaccination numbers dropped at startling rates (Donvan, & Zucker, 2016). Therefore, scientists went into overdrive to determine if vaccinations could really be a causing factor for autism. Yet time and time again studies found that Wakefield was unjustified for his claims. The scare was all for nothing (Donvan, & Zucker, 2016).

Numerous scientists have since carefully reviewed Wakefield's work and found it to be shoddy science, so much so that it was actually retracted from the *Lancet*. He lacked several of the qualifiers needed to make it a legitimate study like including a double blind or control subjects (Gerber, & Offit, 2009). Additionally, scientists have combed through mass amounts of medical records and conducted their own experiments, concluding that vaccines do not cause autism (Gadad et al., 2015; Gerber, & Offit, 2009). They soundly expunged theories involving mercury, overstressing the immune system, and really anything else that could possibly relate vaccinations to autism (Gerber, & Offit, 2009; Uno, Uchiyama, Kurosawa, Aleksic, & Ozaki, 2015). Yet even though there is sound concluding evidence of the safety of vaccines, the damaging effects are still prevalent today. Several parents are still wary of vaccinations because of one faulty study, some

going as far as not vaccinating their kids and leaving them to the very real risk of infection.

While vaccines may not be harmful, it doesn't mean other exogenous agents should be forgotten. For example, there are several compounds, both natural and manufactured, that are identified as teratogens, which are substances that specifically impair the development of a fetus or new born (Teratogens). At even small doses, teratogens can be hazardous. Some of these compounds have been directly related to autism on the hypothesis that they could cause genetic or cellular mutations that could alter brain connectivity, brain functionality or the structure of the neurons themselves (Wong, Wais, & Crawford, 2015). What is frightening is that the list of compounds potentially related to autism is staggering.

In 2012 alone, 70,000 different kinds of chemicals were produced in the U.S (The Chemical Industry in the United States). A study in 2000 reported that about 80% of those chemicals are not tested to see if they have the potential as a tetragon (Wong et al., 2015). A different study found that out of the 413 chemicals that are recognized as toxic, 69% of those could be found in the umbilical cord of newborns (Wong et al., 2015). 54% of the chemicals found in the umbilical cord were discovered to adversely effect the brain (Wong et al., 2015). What is important to note about this number is that the study did not specific whether or not these levels were high enough to be considered toxic.

Part of that 54% is just in the air we breathe, or more specifically the pollution in it. Scientists believe that air pollution is an autism risk factor, because it can cause brain swelling, biological stress and, with long enough exposure, gene mutation (Kalkbrenner,

Schmidt, & Penlesky, 2014; Wong et al., 2015). Yet even with its association with autism and with poor health in general, it is practically inescapable. Air pollution includes substances such as car exhaust, factory emissions, certain types of smoke, and even some cleaning products (Kalkbrenner et al., 2014; Wong et al., 2015). All mandatory parts of the society that we live in. Some of this inescapable pollution also contains toxic heavy metals, such as arsenic, lead, and mercury, which have been associated with developmental issues (Wong et al., 2015). The risk with these heavy metals is that not only are they commonly present in our environment, but they have the tendency to store and build up in our bodies (Wong et al., 2015). This suggests that even if an expecting mother is cautious, she could still be exposing her fetus to the heavy metals that have laid dormant inside her (Wong et al., 2015). While these concentrations may not have presented a problem to the mother, they could be highly deleterious to the baby, causing further developmental problems.

Another part of that 54% is present in the products we consume daily. For example, pesticides, often used for the protection and production of produce, have been shown to alter the morphology of a brain, cause biological stress, and overall impede the development of the brain (Wong et al., 2015). This is alarming considering one billion pounds of pesticides are applied to food in the United States (Alavanja, 2009). While many of us try to be careful by washing our fruits and vegetables, it is practically impossible to avoid common everyday products like plastics, certain types of meats and dairy products, alcohol, tobacco, and medications (Wong et al., 2015). While some of these

seem harmless, these too have chemicals associated with neurodevelopmental disruption (Wong et al., 2015).

While these barrage of chemicals seem intimidating enough, one has to consider other environmental factors when contemplating all the exogenous risk factors. Autism has been related to factors such as parental age, maternal stress, poor nutrition, exposure to infection during the fetal stage, and low maternal intelligence (Fakhoury, 2015). Overall, when considering all the exogenous features that have been associated with autism, it is apparent that society is exposed to a plethora of risk factors. One has to keep in mind that when looking at this daunting list, these factors are only *related* to autism (Fakhoury, 2015). There has been no conclusive evidence to show that any of these factors solely cause autism. It is also important to remember that it is unlikely that just one of these factors alone causes autism (Fakhoury, 2015). It is more likely that a conglomeration of factors would need to be present for autism to be cultivated in a child (Fakhoury, 2015). Long story short, there is no reason one should keep their child in a bubble for fear they might get autism from their environment, they probably will not.

While autism appears to be strongly connected to exogenous factors, it is also highly related to genetics. If one identical twin has autism, there is an 80% chance the other twin will have autism as well (Ecker, Spooren, & Murphy, 2013; Fakhoury, 2015). Other studies claim the odds can be as high as 90% (Deng et al., 2015; Solomon, 2012). These probabilities classify autism as a highly heritable disease. Yet while there are 103 different genes and 44 different genome locations associated with autism, only a few are actually recognized as causing autism. (Carter, & Scherer, 2013; Misra, 2014). These few

specific genes only account for the etiology of 10-15% of the autistic population (Carter, & Scherer, 2013). For a disorder that is strongly genetically related, there are still several unknowns involved with it.

What is even more confounding about the genetics of autism is that researchers are not sure what these genes actually biologically alter to create autism (Mohammadzaheri et al., 2015). Some researchers hypothesize that there is general neuronal disruption in people with autism, indicating the neurons of their brains never developed correctly and therefore function incorrectly. (Bacon et al., 2015). Other researchers believe that people with autism have a more specific deficit called synaptic disruption, which is when the connections between neurons do not form correctly. (Ecker et al., 2013; Speed et al., 2015). Such disruption can cause issues in neurological communication, understanding, and learning considering all these activities need stable and reliable synapses (Ecker et al., 2013; Speed et al., 2015).

Other researchers believe that the issue, while it still involves synapses, is more all encompassing. They believe there is an incorrect level of connectivity within the brain (Cerliani et al., 2015; Solso et al., 2015). Whether its too much or to little is still debated. Some studies have found overconnectivity in the frontal lobes of young individuals with autism, but noted that the overconnectivity decreased with age, while other studies have found overconnectivity between sensory cortex and subcortical structures (Cerliani et al., 2015; Solso et al., 2015). Yet other studies have found opposing information claiming that people with autism are likely to have underconnectivity from the frontal lobe to other regions of the cerebrum (Bhat et al., 2014; Fakhoury, 2015). Because of these mixed

results some believe that it is actually a combination of both overconnectivity and underconnectivity that leads to the symptoms of autism (Hutsler, & Casanova, 2016). Overall, this abnormality in connectivity can result in under or over stimulation in certain areas which can result in autism symptoms, especially sound sensitivity, social difficulties and physical insensitivity (Cerliani et al., 2015).

Still others believe that the etiology of autism is more general in terms of anatomy and believe there is an alteration in the morphology of the brain (Bhat et al., 2014). Some researchers have noted that ASD patients have thinner cortical layers than the average population, while others have noted initial accelerated cerebral growth (Bhat et al., 2014; Hutsler, & Casanova, 2016). Yet others believe that the problem is not anatomical or structural at all, but instead chemically driven (Farmer, Thurm, & Grant, 2013; Ratajczak, 2011). Several researchers have found abnormal levels of neurotransmitters such as acetylcholine, GABA, glutamate, serotonin, and/or oxytocin in the brains of ASD individuals (Farmer et al., 2013; Ratajczak, 2011). Honestly there are several theories behind the biology of autism, but none have been proven to be the cause of autism behaviors. There are some theories that have been highly associated with individuals with autism, but none that have been proven to cause autism.

Overall, while our strongest leads for the cause of autism are probably its genetics and neurobiology, we are still no closer to finding a singular cause for autism. But if one considers autism as a whole, this makes sense. Autism is presented in several different phenotypes. With several different phenotypes comes the possibility that there might be different causes for each of these phenotypes as well. While this theory is understandable,

it does make it difficult to explain to parents why their child has autism. It also makes it difficult to treat autism considering different causes means different solutions. And yet, still we try.

### Chapter 3: How is Autism Treated?

Treating autism is a challenge. As described earlier autism has no clearly defined etiology and has the potential to have several causal factors involved (Mohammadzaheri et al., 2015). This ambiguity in cause makes it extremely difficult for researchers and physicians to identify an adequate treatment. On top of this ambiguity autism is often comorbid with several other disorders (Jang, & Matson, 2015; Mannix, 2016). Some studies have found that approximately 70% of the autism community has comorbidity with at least one other disorder (Jang, & Matson, 2015; Mannix, 2016). The comorbidities that most people with autism have to endure are seizures, anxiety, depression, OCD intellectual disabilities, physical conditions gastrointestinal issues, sleep disturbances and other psychological conditions (Doshi-Velez, Ge, & Kohane, 2014; Lake, Milovanov, Sawyer & Lunsky, 2015; Matson, & Goldin, 2013; Storch et al., 2015). One study found within their group that 33% of their participants with autism have psychiatric disorders and 77.5% have seizures (Doshi-Velez et al., 2014). Also, research indicates that the likelihood of comorbidity increases with the autism severity (Jang, & Matson, 2015). Therefore, not only do individuals with autism and their families have to deal with the challenges of autism, but they have a higher probability of facing other issues as well. Additionally, the probability of comorbidity, and therefore the difficulties, worsen as the severity of autism increases (Jang, & Matson, 2015).

Because of the comorbid aspect of autism, the autism community itself is a highly medicated group. According to studies, about 33% to 66% of people with autism are on some type of medications (Coury et al., 2012; Esbensen, Greenberg, Seltzer, & Aman,

2009; Schubart, Camacho, & Leslie, 2014). One study claimed that percentages were as high as 60% to 80% (Lake et al., 2015). Studies have also shown that individuals with ASD are more likely to become medicated as they get older (Esbensen et al., 2009). This has been attributed to the phenomena that most individuals' with autism symptoms change as they get older requiring different treatment. Medication is also used increasingly with age because other treatment options such as therapies and interventions are often not available for the older ASD population (Esbensen et al., 2009).

Even though it appears that several ASD individuals are able to receive medication, it doesn't necessarily mean that they are being adequately treated. This is due to the fact that most individuals with autism are insensitive to the treatment aspects of their medication (Williamson, & Martin, 2012). Therefore, not only are ASD individuals more prone to a higher comorbidity of issues, but they are less able to treat them as well (Mannix, 2016; Williamson, & Martin, 2012). While some may think the solution would be to just raise the medication dose, this is not a reasonable solution. Raising the dosage would only put ASD individuals closer to overdosing and expose them to more side effects (Solomon, 2012). This is especially troubling considering several individuals with autism are actually more sensitive to the deleterious aspects of their medication (Mannix, 2016; Williamson & Martin, 2012).

Medicating individuals with autism is further complicated by the fact that several ASD individuals find it difficult to communicate their needs (Lake et al., 2015). Already 50% of the ASD population is nonverbal, indicating they cannot communicate when they feel a medication is effective, ineffective or harmful (Goh et al., 2013). While the other

50% of the ASD population may be verbal, they also find it more difficult to communicate their needs, feelings, or distress. So while these individuals may be able to express that they don't want to be on a specific medication, they often cannot express why (Lake et al., 2015). Because of their inability to communicate, caregivers often have to monitor and make decisions about the medications being used (Lake et al., 2015). Caregivers find this difficult because of the lack of feedback they get from their charge (Lake et al., 2015). Most caregivers are only able to identify issues through careful observation of their charge's actions (Lake et al., 2015). While this seems complicated within itself, caregivers find it highly challenging because of the lack of information (Lake et al., 2015). Parents and care providers are fearful that the medication will cause long term negative side effects on their charge (Lake et al., 2015). Others are angered that often doctors are not sure what medication to give their child or whether or not it will even be effective (Lake et al., 2015). Often parents have to determine which medication is right through trial and error and their own investigation. My own family has experienced this. When we took Tyler, my brother, into a neurologist recently the neurologist explained there were a few medications we could try, like Amantadine, which usually is used for Parkinson's treatment (Cera et al., 2014; Raz, Lev, Orbach-Zinger, & Djaldetti, 2013). We tried this for a couple weeks and found that it didn't work. Tyler was then switched to an anxiolytic medication. This medication appears to be working. I say "appears" because we have to observe his behavior carefully to see if there are any changes. Since Tyler is nonverbal, it is difficult to determine if this medication is effecting him adversely as well. Additionally, my family has no clue what type of dosage

we should be giving him, and whether raising or lowering his dosage is appropriate or not. We are still left with several questions even after we visited and received treatment advice from a neurologist who has extensive experience with special needs and autism individuals.

While the autism population is a highly medicated group, there are actually only two drugs certified by the Food and Drug Administration to use for the specific treatment of autism: Aripiprazole and Risperidone (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015). It's shocking to consider that out of all the medications given to this population only two drugs are recognized to treat the core symptoms of autism. Both Aripiprazole and Risperidone are classified as antipsychotic medications, which means they are commonly used to treat schizophrenia as well (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015; Williamson, & Martin, 2012). In autism these medications seem to help lessen the likelihood of outbursts, hostility, repetitive behavior, high energy, and self harm (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015; Williamson, & Martin, 2012). Yet, even though these drugs are approved to treat the core symptoms of autism, they don't treat all symptoms (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015; Williamson, & Martin, 2012). Considering the limitedness of medicinal treatment, one would expect these drugs to be more comprehensive in treating the other symptoms of autism including socialization issues and hyper focus. Additionally, Aripiprazole and Risperidone have controversial side effects (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015;

Williamson, & Martin, 2012). Risperidone needs to be given in high doses to cause a significant effect, and can lead to side effects such as sleepiness, weight gain, increased desire for food, and increased salivation (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015; Williamson, & Martin, 2012). Aripiprazole causes a weight increase in individuals as well, yet there are mixed results about its effectiveness (Pharmacotherapy options in autism: Serious adverse effects, little efficacy, 2015; Williamson, & Martin, 2012). Weight gain can be especially deleterious if the individual is already overweight or has a difficult time accessing or wanting to engage in physical exercise. Overall, while these medications could be beneficial, they also have serious consequences to consider as well.

Researchers have realized that the medicinal treatment for autism is limited, therefore, over the past couple of years there has been a large boom in research for potential medicinal treatments of autism. The research is extremely difficult considering the ambiguity of the etiology of autism. Yet, even with these difficulties, researchers are still investigating options. As shown with Risperidone and Aripiprazole, antipsychotics seem to be a potential treatment for certain aspects of autism (Farmer et al., 2013; Williamson, & Martin, 2012). Antidepressants seem to be effective as well for treating OCD aspects of autism (Farmer et al., 2013). This is due to the possibility that individuals with autism are deficient in serotonin (Farmer et al., 2013). Therefore, antidepressants may be effective because of its ability to increase the amount of serotonin available to the nervous system (Farmer et al., 2013). Cholinergic agents are also in the newer areas of research for autism treatment (Farmer et al., 2013). This is because of the possibility that

ASD individuals may have an abnormality in the amount of acetylcholine they contain. Glutamatergic agents are also being reviewed for autism treatment on the hunch that people with autism have glutamate abnormalities as well (Farmer et al., 2013). Finally, oxytocin seems to be one of the most promising new drugs considering it is a chemical directly related to developing bonding and social behaviors (Farmer et al., 2013). The challenge of this drug is the route of administration, because it is quickly transformed and has difficulty getting to the brain (Farmer et al., 2013). As one can see, there are several possible routes for medicinal treatment and the research community is investing a lot of money to try and determine which ones are effective (Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), 2016). In 2015 alone the NIH spent 208 million dollars on autism research (Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), 2016). Yet because of the variety of options and the numerous unknowns about the causes of autism, it may take some time for these medications to be shown useful, let alone available.

Treatment for autism, luckily though is not limited solely by medication. Several researchers and professionals of autism suggest interventions can help improve someone's ability to function (Roberts et al., 2011). Intervention usually means some type of therapy to help deal with the child's socialization skills, behavioral abnormalities, their stereotypies, etc. (Roberts et al., 2011; Treatments & Therapies). Initially this seems useful and straight forward, yet even in this area of treatment, there are several factors and unknowns. For example, while 15 to 25 hours of intervention a week are suggested, several researchers are not sure how much intervention is best for a child with autism

(Roberts et al., 2011). This is because of the wide variety of autism that exists (DSM-5, 2013). Specifically, because of the individuality of each person and the several expressions of autism, it is often difficult to assess how much intervention is needed or how often (Treatments & Therapies). Additionally, there is controversy about which type of intervention is best (Roberts et al., 2011). To add on to the difficulty of choosing an intervention, there seems to be an endless list to choose from. Autismspeaks.org describes fifteen different kind of intervention therapies alone (Treatments & Therapies). One study found that there were at least 413 interventions, whether they were scientifically based or not, that had been used by parents to treat autism (Carlson, Stephenson, & Carter, 2014). Yet even with the staggering amount of treatment options, a research team reviewed several articles in an attempt to determine the most commonly used interventions (Carlson et al., 2014). They found that speech therapy was the most highly used intervention with an average of 70.2% of parents using it for their child (Carlson et al., 2014) Speech therapy focuses on the physical and social aspects of speaking (Treatments & Therapies). As stated earlier, about 50% of the autism population cannot speak (Goh et al., 2013). Therefore, for non-vocal individuals, speech therapists work on the physical mechanisms of speaking and help them to be able to produce sounds, words, etc. (Treatments & Therapies). For the other 50%, they may be able to speak but don't necessarily understand what is appropriate or misunderstand the meaning of something (Treatments & Therapies). Speech therapists would work with these individuals to use their language skills in a more socially acceptable manner or correct their associations/meanings of words (Treatments & Therapies). After speech therapy,

occupational therapy came as the second highest used intervention with an average of 49.2% of parents who have used it (Carlon et al., 2014). This therapy focuses on assessing helping individuals being able to cope and live in society as best as they can manage (Treatments & Therapies). Therapists would assess cognitive function and physical ability of a child with ASD to determine skills that the individual could develop to become better integrated into society or become more independently functioning (Treatments & Therapies). The remaining top six most commonly used treatments were CAM, medication, TEACCH and Applied behavior analysis (Carlon et al., 2014) CAM stands for Complementary and Alternative Medicine (Mayo Clinic Staff). For autism such treatments can include special diets (like gluten free diets), supplements and vitamins, etc. (Treatments & Therapies) While this type of treatment may seem easy or convenient there is little scientific evidence to show whether these treatments are valid or safe (Treatments & Therapies). Training and Education of Autistic and Related Communication Handicapped Children or TEAACH focuses on helping individuals with autism learn (Treatments & Therapies). This means designated therapists identify a child's with ASD strengths in information processing and weaknesses. From there the therapists try to enhance the child's learning strengths while also working on their weak methods of learning (Treatments & Therapies). Finally, there is Applied Behavioral Analysis (aka ABA) (Treatments & Therapies). ABA has existed for approximately 40 years and has been shown to be one of the most effective therapies for autism (Borden, 2011; Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2012; Treatments & Therapies). Essentially it works on communication, social and learning skills by trying to

reinforce good behavior with a reward or discourage bad behavior by not reinforcing it (Treatments & Therapies). Overall, it is clear that there are several options to choose from when considering interventions for a child with autism. Some studies suggest that whatever intervention a parent chooses for their child though that it should be implemented as earlier as possible for maximum affectivity (Roberts et al., 2011).

While it is encouraging that there is a variety of options available for treatment, it does not mean that it is easy. As stated earlier, interventions can be anywhere from 15 to 25 hours a week (Roberts et al., 2011; Treatments & Therapies). Whether the therapy is at home, in school or at a private institution, these demanding amount of hours can be draining on a parent, when considering the amount of involvement that is needed (Roberts et al., 2011). Additionally, for most therapies to be successful the training/limitations the therapists set up often need to be followed at home as well (Roberts et al., 2011; Treatments & Therapies). This can be stressful for a family to break old habits, spend time learning new habits, and enforce the new habits, especially in the face of tantrums. On top of all this there is no guaranteed success rate. Some individuals will improve dramatically while others will make little progress (Treatments & Therapies). No family will really know how much their investment paid off until the end of treatment. Families though will only have to encounter these difficulties if they can receive treatment in the first place. The Individuals with Disabilities Education Act (aka IDEA) of 1975 mandates that that “children with disabilities are entitled to a public education appropriate to their needs, at no cost to their families” and that “Children with disabilities must be provided with support services that assist them in benefiting

educationally from their instructional program” (Understanding IEP Law and Special Education). In other words, all children with autism in public schools should be getting the type of education and intervention services they need at no cost to their families (Understanding IEP Law and Special Education). This law must be abided in all states. Yet studies are finding that intervention treatments are not adequately provided in public schools (Koenig, Feldman, Siegel, Cohen, & Bleiweiss, 2014; Locke et al., 2015). Several factors lead to this inadequacy. There are over 413 different treatments available and not every child will respond to them in the same way (Carlson et al., 2014; Smith, 2008). Therefore, no public school knows exactly what type of intervention it should have because the needs of its school population is constantly changing (Carlson et al., 2014; Smith, 2008). Additionally, each child affected with autism differs in their phenotype and severity, resulting in differing intervention intensity needed for each child (Smith, 2008; DSM-5, 2013). It is also difficult for public schools to be able to standardize in any way the type of intervention they should focus on or how often it is implemented (Koenig et al., 2014; Locke et al., 2015). On top of all these difficulties, public schools only have a limited budget to work with for their autism population (Koenig et al., 2014; Locke et al., 2015). All these obstacles result in public schools often not being able to provide the type of intervention a child with ASD needs (Koenig et al., 2014; Locke et al., 2015).

Some parents recognize that their children are not getting the appropriate intervention they need from public schools and therefore transfer school districts or look for private therapy at clinics, private practices, private autism schools, etc. (Do Autistic

Kids Fare Better In Integrated Or Specialized Schools? 2014; Fairbanks, 2009). The problem with private therapy or private education is that it often costs additional money, money families may not have (Fairbanks, 2009). Some studies report that it already takes a minimum of \$4,000 to \$6,000 more a year to raise a child with ASD. Other studies put the estimates as high as \$17,000 a year (Cost of Autism: Study Tallies Kids' Higher Health and Education Needs, 2014). Some studies report that when all the math is done, families with ASD will end up spending \$1.4 to \$2.4 million more in their life time than if they did not have a child with ASD (Lifetime Costs of Autism Average \$1.4 Million to 2.4 Million, 2014). Usually these costs are related to medical costs and therapy programs. Therefore, trying to additionally place their children in intensive intervention programs that can run from \$40,000 a year or a private school that costs \$85,000 a year, is usually not possible (Data & Statistics, 2015; Fairbanks, 2009).

In general, while there are plenty of options to treat autism, it doesn't necessarily mean they are effective or accessible, making autism an extremely difficult disorder to treat. Medicines are not as effective as one would hope and often can have deleterious side effects (Farmer et al., 2013). And while interventions seem extremely useful, it is often hard to decide which one is appropriate let alone have suitable access to them (Koenig et al., 2014; Locke et al., 2015). Researchers, parents and school districts though are realizing the difficulty behind treating autism and are progressively taking action to improve the treatment scene of autism. Therefore, while treatment may not be perfect now, with hopefully a combined effort it will continue to vastly improve into the future.

## Chapter 4: How Does Society Deal with Autism?

At this point, it should be easy to see how confusing and complex autism is. It's a complicated diagnosis married with ambiguities in cause and treatment. What is also evident though is that our knowledge about autism has vastly improved as well. When autism was first diagnosed in 1943, there was practically no research on it. It was surrounded purely by speculation and theorization. Yet within the past couple of decades, the research community has been striving to discover and learn more about autism (Donvan, & Zucker, 2016). As a result of this interest, autism research is now booming. This year alone the National Institute of Health intends to spend \$216 million in furthering our knowledge on autism (Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), 2016). While this number seems enormous, it is practically dwarfed when considering the NIH has spent over \$774 million in its research in only the past four years. (Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), 2016). As a result of this research boom, literally millions of sources exist about autism. Looking at Google alone, the word "autism" will produce about 72,100,000 different results (Google, 2016). That's more than what dyslexia, schizophrenia and OCD have combined (Google, 2016). As a result of this boom of knowledge, societal perceptions of autism have made leaps and bounds as well. People with autism are no longer shoved away into asylums to be forgotten or barred from schools. In fact, autism is no longer an unknown word. It has spread its way across the news, media, entertainment and everyone's mind. Seldom can anyone exist in modern society without hearing the word "autism". Yet for all the progress that has been

made in the past 76 years there are still some large deficits in how society deals with autism. One can be found surprisingly within the medical community.

One would expect a medical professional such as a pediatrician or general practitioner to be well versed in autism. After several years of training and also focusing on a cohort that is especially susceptible to autism, it would be easy to assume that it is part of their repertoire. This has shown not to be the case. A group of researchers found that parents of children with autism have been highly unsatisfied with the quality of care and knowledge that they receive from their doctors (Lake et al., 2015). Most claimed that their doctors could only diagnose their child, describe what autism is and then provide them with a medication that they had little to no knowledge of (Lake et al., 2015). The parents complained that they or their children often had to do their own research and experimentation to find what medication was right for their child with ASD (Lake et al., 2015). They felt as if their doctor should know this information. They also commented that the medical professionals appeared to have a lack of understanding for their situation resulting in parents feeling misunderstood and impoverished in empathy. (Lake et al., 2015). Additionally, the parents commented that their child with ASD often had a difficult time attaining non medicinal aids like therapy or interventions (Lake et al., 2015). They heavily criticized this aspect of the medical field because they knew from the literature that such non medicinal treatments could be highly beneficial for their child (Lake et al., 2015). Overall, parents and families with ASD children felt as if they had underwhelming support from the medical community.

I can personally corroborate this sentiment with our family's own experience. For several years, pediatricians, while they were great doctors, could not identify that Tyler had autism. Instead they claimed that he was "developmentally delayed". Beyond that, they couldn't tell you much. It wasn't until a year ago, when Tyler was 24, that a neurologist finally identified that Tyler had autism. Yet he didn't bother to explain to us what autism was, how it could be caused or how it could be treated. Instead he only offered a medication that he said would probably not work and sent us on our way. That's it. He didn't bother to explain why the medication wouldn't work, different routes of treatment, nothing. We went in searching for answers and came out with only a single word answer, autism.

Research has also found that doctors are poor at enacting early screening and preventative care for autism as well. With a 1 in 68 chance that a child could have autism, one would think that doctors would be screening every child they examined to see if they have it (Facts About ASD, 2015). The CDC itself states that pediatricians should be screening their patients at "18, and 24 months" (Screening and Diagnosis, 2015). Fortunately, it is relatively easy to screen for autism, takes limited resources, limited training, and a limited amount of time (Screening and Diagnosis, 2015). Yet even with the ease of testing and the CDC's suggestion, a report states that only 8% of pediatricians actually screen for autism in their patients (Quirantes, 2009). The fact that most pediatricians do not follow these guide lines is alarming considering early diagnosis and intervention is often considered quintessential for people with autism to be able to thrive (Roberts et al., 2011).

The deficits are not only glaring in the medical community but in the scholastic community as well. As discussed earlier, in 1975 IDEA was passed to ensure that special needs children, including people with autism, were getting “free and appropriate public education” (Winters & Green, 2007). While it is undeniable that the special education programs today are vastly superior to years past when these programs didn’t even exist, the education system in place is still not enough. (Donvan, & Zucker, 2016). Policy makers, parents and school systems constantly comment on how IDEA is underfunded in the public sphere making it more difficult to secure the services that children with autism need (IDEA/ Special Education ID, IDEA Funding – EdCentral). Some sources note how state support continues to decrease as time goes on while others claim that the government only secures 15% of the amount they actually designated for IDEA (Understanding IEP Law and Special Education). This lack in budgeting makes it difficult for parents to get services they need for their children to fully succeed and often have to go into legal action, a process that is often long, arduous and expensive (About special education). Studies are also showing that along with budgeting issues, schools are having a difficult time implementing effective intervention programs as well, something that is critical for the development and education of individuals with autism (Schultz, Schmidt, & Stichter, 2011).

Some parents feel that the level of education offered is not the only deficit of schools (McKenna, 2014). Some believe they don’t provide a very nurturing environment either, which stunts their child’s with ASD ability to develop and grow (McKenna, 2014). Part of the concept of the IDEA act is that special needs children are able to access their

education in the “least restrictive environment” (Individuals with Disabilities Education Act, IDEA). This means that, if possible, children with autism and other special needs individuals should be able to receive their education in the same environment as their peers. If their disabilities are too severe though, they are often contained to a separate special education class (About special education). Parents claim that whether their children with autism are in a “normal” class or a special education class, they are still socially isolated and lack an inclusive environment (McKenna, 2014). Part of this is due to the lack of education about autism in schools (Obeid et al., 2015). Research shows that because of this lack of knowledge, children are more likely to bully individuals with autism and much less likely to interact with them (Obeid et al., 2015). Parents argue that for someone who already has socialization issues, this kind of isolating environment makes their own personal isolation even worse (McKenna, 2014).

Throughout my own primary and secondary education, this was the case as well. Never did you see a “special needs individual” in class and there was often little to no involvement with the “special needs” peers. The only time we really ever saw them was during lunch time when they were isolated to their own table. Rarely did anyone talk or interact with them. Additionally, we were never educated about autism, Downs Syndrome, schizophrenia or really any other disorder. We were never educated about what these disorders were, the difficulties associated with them, or even encouraged to interact with them. The only ones we were informed of were disorders that could affect us like depression or anxiety. Overall, I can personally attest that the support and inclusion of people with autism and other special needs children is severely lacking.

Unfortunately, this lack of understanding and support does not stop in schools, its prevalent throughout society. While it is true that practically everyone has heard the word autism, not everyone understands what it really means. A study found that more than half of the people it surveyed thought that autism has a cure when it is quite clear that it doesn't (Autism misconceptions). A different study found that people are often misinformed about the commonness of autism, what autism is, or how it occurs (Obeid et al., 2015). As a result of this lack of knowledge, studies have identified that people of the public have several misconceptions about autism (Obeid et al., 2015)

One particular misconception is the belief that people with autism often have advanced intellectual abilities or are savants (Common Myths; Draaisma, 2009). While society thinks that people with autism are often strange or bizarre, they believe these qualities are offset by the astounding intellect they all possess (Draaisma, 2009). Most people don't realize that only 10% of the autism community is comprised of savants (Treffert, 2009). Part of the reason for this gross misconception is not only the lack of knowledge about autism, but the media as well. The media and entertainment have used and highlighted the story of the savant individual with autism to make it seem more glamorous, approachable, and, honestly, more sellable (Draaisma, 2009) Yet on the other side of the spectrum some think that autism is only associated with a severe intellectual deficit. They fail to recognize that autism effects everyone differently and that while some are intellectually impaired others are of average or greater intelligence (Draaisma, 2009).

Then there are the people right in the middle of these two camps. They will say things like “oh sorry, I’m acting autistic” or “well really everyone is on the Autism Spectrum”. Some people believe that it is a disorder that is common to everyone (Draaisma, 2009). While autism does affect a large amount of people, it is not true that it affects everyone. By claiming that everyone is slightly autistic, people are trying to make it a more relatable experience (Draaisma, 2009). While this can be admirable, it also down plays the significance autism can have on an individual and their family. It makes their difficulties that they face every day seem common place and therefore unimportant or over emphasized.

Some recognize that everyone is not on the Autism Spectrum yet make the erroneous assumption that whoever is on it is malicious (Common Myths). For example, on a TED talk, an individual claimed that she went to google autism and found that the first phrase that popped up was “autistics are demons” (King, 2014). This experience coincides with the opinion in society that individuals with autism are often violent and harbor no emotions, both of which are far from the truth (Common Myths). Unfortunately for our family, we have seen this opinion several times. When we take Tyler out into public, people will often stare or try to steer clear of him. Commonly the emotion expressed in their eyes is fear, confusion or disgust. They think because he flaps his hands or makes funny sounds that he’s evil or dangerous, which for us is extremely distressing considering we know that is the furthest thing from the truth.

Overall, while society’s understanding of autism has increased greatly over the past 76 years, there are still some shortfalls as well. There are several varying views of

autism, some of them being right, but most of them drastically wrong. As a result, people with autism are often wrongly isolated, ignored or even harmed (Obeid et al., 2015). So while yes, people with autism are now allowed to exist in society, that doesn't necessarily mean they get to thrive.

## Chapter 5: How Ought We to Live with Autism?

This issue in societal perception may not seem like a big deal if one has had no personal experience with it. But I do. Therefore, I have faced the desolation that grows in a family when there is a lack of knowledge or understanding at a doctor's office. I have seen my parents fight in vain with the school district just so Tyler could receive the basic education that "normal" people are blessed to have. I have experienced the frustration over my fellow peers' lack of understanding and acknowledgement of autism. I have felt the rage that boils when someone gives my brother a fearful or judgmental look, just because he acts differently. And I have had the urge to kill when I merely hear a whisper that someone made fun of my brother. The worst part of it is, my brother has done nothing to deserve this gross misunderstanding and societal neglect. He has the innocence of a child and yet still gets treated like a reject. Not one person deserves such treatment. Yet in our society, it is not just one person being treated like this. When the numbers are crunched, there is actually a potential that 4,689,705 Americans and their families are being treated like this (Data and Statistics, 2015). So yes, this is a really big problem. So, how do we as a society fix it? Personally, I think the overarching answer is increased education.

The first place a major educational shift needs to occur is the place where autism is first diagnosed and cared for, the doctor's office. A study by the American Medical Association Journal of Ethics identified that pediatricians in their residency are simply not learning enough about autism (Major, 2015). This lack of education leads to the lack of support reported by parents in the doctor's office (Lake et al., 2015). Without the

proper education how can a doctor accurately emphasize with their ASD population or provide the education, screening and services they need? There is currently an ASD education program that is being developed and tested called the Autism Case Training Curriculum or A.C.T. (Major, 2015). It has been designed by Developmental-Behavioral Pediatrics programs and includes seven case examples for learning about and identifying autism (Major, 2015). The AMA Journal of Ethics conducted a study to see how effective it was in residency training programs, and they concluded that while it did help to increase short term knowledge about ASD, the level of knowledge being demonstrated by residency pediatricians was still subpar (Major, 2015). This indicates that ASD education is still lacking in the medical field. To rectify this, programs such as the A.C.T. should be modified and strongly implemented into residency programs to raise doctor's education level and awareness of autism.

This increase in education would improve the medical systems response to ASD patients in several different ways. Primarily the education would raise a doctor's awareness and knowledge of autism, which should allow them not only to sufficiently help and educate their ASD patients and families, but emphasize with the difficulties and struggles they face as well. This alone will help improve the treatment and support that is currently lacking within the medical field.

The increased education would also help in the deficit of early screening seen today. Dr. Katharine Zuckerman, a pediatrician in Oregon, states that the lack of early screening is an issue primarily because doctors do not know how to screen for autism (Some Doctors Dismiss Parents' Concerns About Autism, 2015). Rebecca Landa, an

official at the Center for Autism and Related Disorders, also states that pediatricians are constantly bombarded with “overly worried” parents (Some Doctors Dismiss Parents’ Concerns About Autism, 2015). This lack of education combined with the expectation of parent hypersensitivity is what causes doctors to brush off parents’ worries of autism and not perform screenings for it. An increase in education about autism in the medical field would enable pediatricians to be able to screen for autism in every child they treat. Additionally, if mandatory screening was implemented into pediatric practice, physicians would not have to rely on “overly worried” parents to determine whether or not screening should be performed, they would just do it regardless. Earlier screening would be beneficial to ASD families because it would provide them an earlier access to treatment and therefore possibly greater results in their ASD child’s functionality (Roberts et al., 2011).

Even if screening wasn’t an issue, the ability to diagnose a child with autism is. Dr. Zachery Warren, a “director at the Treatment and Research Institute for Autism Spectrum Disorders” states that along with the severe deficit in screening there is also a lack of diagnostic professionals available for autism (Training Pediatricians to Fill Need for Earlier Autism Diagnosis). This leads to families having to wait for months to confirm that their child has autism. Not only is this waiting period stressful on the families, it prolongs treatment (Training Pediatricians to Fill Need for Earlier Autism Diagnosis). The early intervention so strongly recommended by professionals lays contingent on the availability of a firm diagnosis. Without it, ASD families cannot access those resources, prolonging the period their child remains untreated (Understanding IEP

Law and Special Education). The increase in education of autism in the medical field would hopefully solve this deficit in one of two ways. The first is that the increased education of autism in residency would inspire more pediatricians to specialize towards diagnosing autism, therefore closing the gap in the diagnosing deficit (Training Pediatricians to Fill Need for Earlier Autism Diagnosis). The second possibility is if ASD education increases to the extent where the pediatricians themselves could not only be screening for, but diagnosing the autism as well (Training Pediatricians to Fill Need for Earlier Autism Diagnosis). While this might take more time to implement, this would certainly solve the deficit of diagnosis. Therefore, families would no longer have to spend months worrying about the predicament of their child, but instead just a few weeks to confirm their child's condition and start taking the actions necessary to receive treatment.

Overall while this education implement will take some time, it is necessary to make this reform starting now. The ASD population is continually increasing and therefore an increasing amount of people are not receiving the medical care they need. The Hippocratic Oath itself states that doctors must “apply, for the benefit of the sick, all measures which are required” (Bioethics). This lack of education in the medical field is causing doctors to fail in providing “all measures which are required” such as autism screening. The Hippocratic Oath also states that doctors “will remember that there is art to medicine as well as science, and that warmth, sympathy and understanding may outweigh the surgeon's knife or the chemist's drug” (Bioethics). While this is required of doctors, several are often failing to provide the “warmth and sympathy” so many ASD families desperately need because doctors lack the knowledge to be able to be

“understanding” (Bioethics). In actuality, this lack of ASD education is not only effecting ASD families but doctors as well. They are not able to fulfill their duties or reach their potentials because of their institutions lack of ASD education. Therefore, increased ASD education is a must so doctors can perform to their fullest capability and fulfill what they were sworn to do. This fulfillment of their duties will then transcend down to their ASD patients and allow them to receive the treatment, empathy and knowledge the ASD population desperately needs.

Education should not only be increased in the medical system but in the public education sphere as well. Unfortunately, increased education means increased funding, something we all know is desperately lacking and that several parents, politicians and concerned citizens have been advocating for an extended period of time. There are obviously a whole slew of reasons why increased funding would improve education, but it would specifically affect the ASD population by improving schools’ special education programs. With increased funding, school districts could bring in more specialists associated with autism, so ASD children can get the appropriate interventions, and therefore education, that they need and that the IDEA act states schools will provide. By improving the special education system in schools, home life can be amended as well. With increased funding, parents may not have to fight with the school district or dig into their own pockets for the services their child needs to succeed. This decrease in financial burden could improve the overall quality of home life of an ASD affected family by reducing one of the many stresses associated with autism (Whitehead, Dorstyn, & Ward, 2015).

The increased funding should not be reserved for just the special education programs. Some parents suggest that additional funding should go towards activities where ASD children and “normal” children could intermingle (McKenna, 2014). This, they claim, would cause ASD children to be less ostracized and more involved within the school community. While this is a valiant idea, it does not address the core issue of why isolation occurs. People with autism can express some particular, aversive, or odd behaviors. On top of this, other “normal” children are not really taught anything that is outside of their own “norm”. Therefore because of a lack of education, kids often do not know how to rationalize the odd behaviors of autism, which leads them to labeling kids with autism as either just strange, rude or different (Donvan, & Zucker, 2016; Solomon, 2012). With these labels comes ostracizing. Nobody wants to hang out with the rude or strange kid. So instead they just ignore them (Donvan, & Zucker; Solomon, 2012). A lack of ASD education is the driving core problem of why people with autism are often isolated.

The remedy to this issue is relatively simple. Use additional funding to teach kids about disorders that are outside their norms like autism, schizophrenia, etc (Gillespie-Lynch et al., 2015; Obeid et al., 2015). Not only will it help expand their base of knowledge it will help kids understand the things that exist outside their norm. ASD and other such disorders would no longer be foreign to them. Studies have shown that when education about autism is implemented into the educational curriculum, stigmas and misconceptions about autism tend to decrease (Gillespie-Lynch et al., 2015; Obeid et al., 2015). Education about autism could essentially help kids be more understanding towards

their peers with autism. Therefore, instead of giving the kid that is acting strange the label of “different” or “off”, they may think to themselves “hey I know what that is, that’s not so weird”. Because they know why the child is acting a little differently, instead of being baffled by their behavior, they may be less timid to approach them or talk to them.

What is beautiful about this education initiative is that it will eventually infiltrate and affect society. Already several individuals with autism themselves have taken to the internet and public speaking to address the misnomers and misperception of autism. But obviously it is not enough if the stereotypes of autism still exist. If more people were to be educated about autism they can join in the efforts in spreading the word about the reality of autism. More people could understand and realize the incorrect media portrayals. More people could help combat the stereotypes of autism and defend those who are being wronged. They can join in the fight until eventually everyone realizes the truth about autism.

## Closing Remarks

I started this project to gain a better understanding of my brother Tyler and the way he is. Now I truly understand how difficult his life of autism is and the daily challenges he must face. And through this understanding, my relationship has actually improved with him. Instead of harboring frustration over his peculiar behaviors, I realize why they occur and that he has no control over them. With this understanding comes a peace and appreciation for who he is and who he will become. This realization alone makes this past year of research more than worth it.

This project though has also made me realize, more so than ever before, that the society we live in is an unjust one. It ostracizes and mistreats people like my brother for just being different, making their lives more difficult and challenging than they need to be. But I also realize through this research that myself and others have the capability to transform our society into a more just and hospitable one. If we could all just work together to implement the education changes I outlined, we could transform society into a more holistic, inclusive and overall *magis* one. I've seen how challenging a day in a life of autism can be. If somehow my educational reform ideas made this life a little easier, than I feel like this project will have *truly* served my brother and fulfilled its purpose.

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