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An Evolving Understanding of a Spectrum “Disorder”

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For Kaylee,

Thank you for always believing in me.

Abstract

The 2013 publication of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) affected millions of people. Individuals who had previously received a diagnosis of Asperger's syndrome (AS), or any other pervasive developmental disorder (PDD) with the exception of Rett syndrome (RTT)[1], suddenly found themselves placed on the autism spectrum. While some individuals with PDDs viewed this diagnostic change as beneficial, others felt that they had been stripped of a part of their identity. By merging several disorders, the DSM created the "umbrella diagnosis" of autism spectrum disorder (ASD), which features an incredibly varied etiology and diverse clinical outcomes. In this thesis, I argue that (a) many people with ASD do not feel impeded in their daily activities and thus do not meet the definition of "disordered," (b) these same individuals display signs of neurodiversity, or natural variations in the human genome, and (c) a diagnosis is a snapshot of someone's life and does not dictate their future experiences. Having received a diagnosis of AS myself, I hope to illustrate a comprehensive portrait of ASD by blending my personal experiences with information on autism research, associated behaviors, assistive measures, and cultural changes.

Keywords: Asperger's syndrome (AS), autism spectrum disorder (ASD), *Diagnostic and Statistical Manual of Mental Disorders* (DSM), neurodiversity, pervasive developmental disorders (PDDs)

[1] Found almost exclusively in females, Rett syndrome (RTT) features a significant reduction in the cortical grey matter present at an individual's birth. The DSM-5 elected not to include RTT on the autism spectrum due to its unique impact on an individual's physiological growth (Solomon, 2017).

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"Not everything that steps out of line, and thus "abnormal," must necessarily be "inferior" - Hans Asperger (1938)

Robert: 2005

Robert is a nine-year old student in the third grade. He was referred for psychological evaluation by his parents and teachers for scholastic and behavioral concerns. Robert's teachers report that he possesses above grade level abilities in all academic areas. However, due to poor organizational skills and issues with distractibility, Robert fails to perform at a level commensurate with his abilities. Robert often forgets or loses his schoolwork and does not appear concerned about, or interested in, completing his assignments on time. Instead of working, Robert engages in recreational activities, including drawing, cutting up paper, and making lists.

Robert presents with a diagnostic history of anxiety disorder not otherwise specified (NOS)[2] comorbid with attention deficit hyperactivity disorder (ADHD). He meets regularly with a child psychiatrist and currently takes medication to increase his serotonin[3] levels. Despite this, Robert often appears preoccupied or anxious. He worries excessively about novel, or imaginary, circumstances and death. When stressed, Robert paces and mutters softly to himself. According to his parents, Robert spends hours at a time walking the perimeter of their property and wringing his hands. He demonstrates no signs of having hallucinations or delusions. Rather,

[2] A "not otherwise specified" (NOS) diagnosis applies to individuals who meet the general qualifications for a disorder, but do not fall into a specific diagnostic category.
[3] A deficiency of the neurotransmitter serotonin, which contributes to an individual's sense of well-being and happiness, typically leads to increased levels of anxiety or depression.

Robert's parents believe that he has adopted this routine as a self-calming technique. The purpose behind the current examination is to determine if Robert qualifies for a differential diagnosis of Asperger's syndrome (AS). His parents and therapist disagree with his current diagnosis and argue that Robert's behavioral abnormalities are more indicative of a pervasive developmental disorder (PDD) than anxiety disorder NOS or ADHD. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) separates the diagnostic criteria for AS into three categories: deficits in social interaction, deficits in social communication, and the presence of restrictive, repetitive patterns of interests or behaviors (RRIBs) (American Psychiatric Association, 2004).

Like many children with AS, Robert experiences significant difficulties with empathy and social-emotional reciprocity. He fails to comprehend how his words or actions affect others. For example, Robert will ask his parents for a favor immediately after they have expressed anger towards him. His parents do not believe that this is an attempt by Robert to "make up." Rather, they argue that he lacks the ability to attribute mental and emotional states to others. Robert also displays reduced levels of shared social enjoyment. He did not request anything for Christmas this year and failed to acknowledge the holiday season. His father recalls the first time that Robert rode a bike: "while the rest of the family was highly excited, he demonstrated almost no emotional response." Individuals with AS, or other PDDs, tend to show a diminished emotional reaction to personal milestones or achievements (e.g., learning to ski or receiving an A on an exam). According to his inclusion teacher, who spends approximately one hour per day assisting him, Robert often appears fearful and remains on the perimeter of his friend group. Robert's parents report that he interacts with peers outside of school less than once per week. On the rare

occasions when he invites a friend to spend the night, Robert will ask his mother how he can convince them to leave early in the evening.

Robert also exhibits evidence of having RRIBs. He demonstrates intense interests in several areas, ranging from animal classifications to literary worlds, and will often lecture about these topics for hours on end. During his monologues, Robert fails to recognize other people's irritation or lack of interest. In addition, Robert compulsively creates lists, typically of 50+ items each, relating to the subjects that have captured his attention. His mother presented a series of lists compiling the names of approximately 70 background characters from the Star Wars films. These lists feature a variety of odd symbols and notations, indicating the presence of an organizational system known only to Robert. According to his parents, Robert "resists almost any kind of change." He responds negatively to rearranged furniture or changes in routine. For example, Robert has consumed the same lunch every day for over five years: a peanut butter and jelly sandwich (always cut vertically), Goldfish, Lay's barbecue flavored potato chips, and a strawberry-flavored fruit roll up. Attempts to modify this meal have resulted in Robert refusing to eat.

Robert's mother reports that he began speaking at an early age and would often sing or mumble to himself. She notes that he possesses above average language comprehension and memory. An important diagnostic distinction between AS and autistic disorder (AD), another PDD, is the presence of a cognitive or communicative delay in an individual's development. Because Robert does not display signs of having experienced such a delay, he would not qualify for a diagnosis of AD. Despite his behavioral quirks, Robert appears perfectly content to entertain himself and enjoys many of the same activities as neurotypical children (e.g., cartoons

and video games). Robert's parents and teachers also describe him as possessing a sarcastic sense of humor and a fondness for animals.

Robert was seen by a team of psychiatrists on four separate occasions in the company of his parents. In each session, Robert failed to acknowledge the presence of examiners. He avoided eye contact and did not respond to any attempts to initiate conversation. While his responses were appropriate, he offered minimal elaboration. Robert scored 114 on the Asperger Syndrome Quotient, indicating a high likelihood of having the disorder. He also fell within the "non autistic" range for the Childhood Autism Rating Scale, which is not sensitive to characteristics associated with AS or pervasive developmental disorder not otherwise specified (PDD-NOS). Based upon Robert's accumulated history, and autism measurements, the team determined that he qualifies for a diagnosis of AS comorbid with anxiety disorder NOS and ADHD.

Personal Connection

Having received a diagnosis of Asperger's syndrome (AS) myself, I feel a personal connection to this topic. During my preliminary research, I discovered several documents detailing my previous psychological evaluations. It felt surreal to read and write about myself in a diagnostic context, and I adopted the pseudonym of Robert to distance myself from the situation. I decided to open this thesis with my personal case study for two reasons: I wanted to introduce the important topics relating to autism and AS in a meaningful way, and I hoped that writing about my diagnosis would help me learn to embrace it. I spent years feeling conflicted about my diagnosis. On the one hand, learning that I had AS provided me with a sense of validation. I knew from observing and interacting with other children that I behaved abnormally, and I often experienced feelings of inferiority or alienation. I believe that Katharine Annear, the

Chair of Australia and New Zealand's Autistic Self Advocacy Network (ASAN), perfectly summarizes my own experience in her statement that "finding Asperger's was like finding a glove that fit" (Annear, 2013). After discovering that other people existed with difficulties and mannerisms similar to my own, I started to perceive my behavioral abnormalities as personality quirks rather than character flaws. On the other hand, I have spent a significant amount of time and energy distancing myself from my diagnosis. I refused to read any published material about AS, despite my parents collecting numerous help books on the subject, out of fear that my behavior would change to fit a written description. Since that time, I have undergone significant personal growth. I no longer feel ashamed of my AS, and I openly share my diagnosis with my friends. My interest in learning more about AS, and the controversial transition to autism spectrum disorder (ASD), provided my inspiration for this thesis.

I do not remember being diagnosed with AS. However, I do recall meeting with various psychiatric professionals throughout my childhood and adolescence. For years, I remained blissfully unaware of the purpose of those meetings. Someone would place a box of toys on the ground and attempt to coax me into answering questions about my thoughts or behaviors. Upon reflection, I realize that I verbally communicated less than I thought. Responding in quick four to five word sentences felt like a big deal to me; I would have preferred not to talk at all. I could read entire books and perform basic multiplication by the age of four, but I could not explain why certain situations or stimuli upset me. I began speaking at an early age and would often sing softly to myself. However, I would rarely share information about my thoughts or behaviors voluntarily. Children with AS or autism tend to be introverted by nature. In my case, I attribute my lack of verbal expression to not knowing how to properly convey my thoughts or emotions.

In addition, I expected those closest to me, primarily my mother, to already understand why I felt or acted the ways in which I did. For example, during my early childhood, I had an intense fear of strangers breaking into my home and harming my family. My nightly routine consisted of me checking every door in my house to make certain that my parents had properly locked them. I also required my parents to make frequent visits to my younger sister's room to ensure her safety. My habitual lock-checking, and associated night terrors, subsided with age, and years later my parents would inquire into my behavior. With the exception of my mother, who managed to coax some information out of me, no one understood why I had so much anxiety around strangers. In hindsight, I must have been one of a select few children who grew fearful at the prospect of Santa Claus visiting.

Throughout my childhood and adolescence, I demonstrated many of the characteristics typically associated with AS. I preferred isolated and repetitive play with toys or objects over social interaction. I found other children annoying, and I grew anxious at the thought of them touching my belongings. My parents arranged social gatherings for me, and I participated in a life skills program at school intended to help children form friendships. Through repeated exposure to social situations, particularly at school, I was able to make friends. I do not believe that I would have benefited socially from being placed in a separate classroom from my peers. In addition to difficulties with social interaction and communication, I displayed a strict adherence to routine and intense interests. Growing up, I enjoyed following a set schedule. Having a timetable of events made each day seem more manageable. Unexpected deviations from that schedule created a sense of unease. While I still like planning my calendar in advance, I no longer feel upset when changes occur. Children with AS typically display narrow fields of

intense interest (e.g., arctic penguins). When a particular topic captured my attention, I would gather copious amounts of information and regurgitate what I had learned to others. My obsessive interests sometimes extended beyond everyday conversation, and I would compulsively create lists. I recently discovered a notebook compiling the names of 70+ background characters from the Star Wars films. Although I still exhibit many of the behaviors typically associated with AS and ASD, like obsessively rewriting this section, I do feel that I have made great strides in my social development. For example, I held a position as a first-year resident assistant at DePauw University. I also joined a social fraternity, where I served as the president and head of risk management. I do not intend to appear boastful or arrogant by sharing this information. Instead, I hope that providing an example of someone who achieved several goals that they believed might not be obtainable (i.e., prolonged and successful social interaction) will encourage others to not set limitations on themselves due to a diagnosis.

Approaching "Disorders"

We live in a society with a skewed perception of mental health. We pathologize, or treat as psychologically unhealthy, any behavior that conflicts with our expectations of the world. The *Merriam-Webster Collegiate Dictionary* (11th ed.) defines a disorder as "a condition marked by lack of order, system, regularity, predictability, or dependability" (Merriam-Webster, 2003). While many people meet this criteria of "disordered," and benefit from therapeutic measures or assistance, not everyone with a diagnosed mental illness feels impeded in their daily activities. According to a 2016 report by the Substance Abuse and Mental Health Services Administration (SAMHSA), approximately one in six U.S. adults lives with a diagnosable mental illness. However, only 4.2% of the population reports having a "serious mental illness" (SMI), a

condition that impairs an individual's ability to execute a regular routine (Substance Abuse and Mental Health Services Administration, 2017)[4]. In response to current diagnostic practices and ableist societal constructs, a growing amount of people have started to promote the concept of "neurodiversity"[5]. Advocating for "neuro-equality," or equal treatment and opportunities for the psychologically "abnormal," the neurodiversity movement argues that many individuals with mental disorders display differences, rather than malfunctions, in brain circuitry (Fenton & Krahn, 2017).

Due to their extensive involvement in many people's lives, approaching the subject of mental disorders requires a great deal of tact and care. In this thesis, I intend to avoid the unnecessary use of medical nomenclature or jargon. Terms such as "symptom," "treatment," and "cause" often carry negative connotations when applied to mental illness. For example, the word "treatment" implies that a "cure" exists. Mental disorders do not have "cures," but therapeutic or assistive measures may help to quell undesired characteristics. In addition, when describing someone with a mental illness, I prefer to place the individual before the diagnosis (e.g., "a person with autism" rather than "an autistic individual"). I believe that this method of description provides an individual with additional agency over their diagnosis. Having a mental illness does not inherently make someone "wrong," and we need to respect the line between constricting an individual's identity and assisting them with their disorder.

In the realm of psychiatry, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) acts as the ultimate authority in determining which neurological and behavioral variations constitute a "disorder." Published by the American Psychiatric Association (APA), the DSM

[4] For more information about the prevalence of mental illness in the United States, visit the SAMHSA website at www.samhsa.gov

[5] For more information about the neurodiversity, or "neuro-equality," movement, see Fenton & Krahn (2007)

releases periodic updates prompted by scientific advancements and cultural changes. For alterations to a DSM diagnostic category (e.g., pervasive developmental disorders) to occur, a work group comprised of professionals in that respective area submits changes for review. Any adjustment made to the DSM requires the approval of several committees: the Scientific Review Committee (SRC), the Clinical and Public Health Committee (CPHC), the DSM-5 Task Force, and the APA Board of Trustees (Kendler, 2013; Solomon, 2017). Despite being the product of expert consensus, the DSM still has its fair share of flaws and critics. Some experts fear that the DSM's diagnostic descriptions are too vague, which may lead clinicians to overdiagnose certain disorders (Pomeroy & Anderson, 2013). Others, including psychiatrist Robert Michels, argue that the current diagnostic process has more cultural than scientific validity: "it is not that [diagnoses] have much to do with science; it is that many people believe that they do" (Michels, 2015, p. 371). The former director of the National Institute of Mental Health (NIMH), Thomas Insel, echoed Michel's sentiment when he declared that the NIMH would no longer use the DSM's classifications in its studies: "Unlike our definitions of ischemic heart disease, lymphoma, or AIDS, the DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure" (Insel, 2013). Despite its shortcomings, the DSM remains the best resource for physicians when diagnosing mental disorders (Pomeroy & Anderson).

An Introduction to the Autism Spectrum

Autism spectrum disorder (ASD), commonly abbreviated to "autism," refers to a cluster of conditions characterized by difficulties with social interaction, communication, and the presence of restrictive, repetitive patterns of interests or behaviors (RRIBs) (American

Psychiatric Association, 2013). Autism-associated characteristics begin to appear at around two to three years of age (Pino et al., 2017). Due to changing criteria and an increased awareness of the disorder, the diagnostic rates of autism have increased significantly over the last two decades (Nelson, 2014). According to a 2016 report by the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Network (ADDN), approximately 1 in 68 children had an autism diagnosis in 2012. In comparison, the ADDN estimates that the prevalence of children with autism in 2000 was 1 in 150 (Centers for Disease Control and Prevention, 2016).

Historical Overview of Autism

Although ASD remains a relatively recent addition to the DSM nosology, the term autism dates back to the beginning of the twentieth century. Originating from "autos," the Greek word for self, the adjective "autistic" was historically used to refer to someone socially reserved or withdrawn. In 1908, Swedish psychiatrist Eugen Bleuler coined the term to describe his patients with schizophrenia, who displayed highly self-focused behaviors and appeared to reside in their own version of reality (Solomon, 2017). In the 1940s, psychiatrists Leo Kanner and Hans Asperger repurposed the label to characterize children with deficits in social interaction, communication, and who displayed restrictive, repetitive patterns of interests or behaviors (RRIBs) (American Psychiatric Association, 2004). Despite attempts to rebrand it as a distinct disorder, autism remained closely associated with schizophrenia through popular perception. In fact, the DSM did not differentiate between the two conditions until 1980, when it introduced the diagnosis of Kanner's early infantile autism (American Psychiatric Association, 1987).

In 1943, Leo Kanner published *Autistic Disturbances of Affective Contact*, an account of his research at Johns Hopkins Hospital with 11 children whom he unofficially diagnosed with "early infantile autism" (Kanner, 1943). Kanner's subjects demonstrated impaired fine motor skills, showed an indifference to the presence of others, and engaged frequently in ritualistic or repetitive play. In addition, many of the youths he observed experienced a delay in their cognitive or communicative development, and spoke primarily through echolalia, the meaningless repetition of words or phrases. For example, one child, Donald, would repeat the word "yes" when he desired to ride on his father's shoulders. Donald associated the word with an immediate action, but proved unable to comprehend the meaning of "yes" in other contexts (Kanner, p. 220). Kanner attempted to distinguish his new diagnosis of early infantile autism from Bleuler's schizophrenia by emphasizing its congenital, present from birth, nature and his subjects' obsessive need for sameness (Kanner). The DSM-III added early infantile autism, also known as "Kanner's autism," to the growing list of developmental disorders. While this inclusion significantly contributed to the recognition of autism as a distinct condition, the DSM-III failed to differentiate between autism and schizophrenia in adults. If an individual displayed autistic characteristics beyond a certain age, they would receive a diagnosis of schizophrenia instead (American Psychiatric Association, 1987; Solomon, 2017).

At the same time that Leo Kanner was performing his case studies in the United States, Austrian pediatrician Hans Asperger conducted research with children whom he believed had "autistic psychopathy," a mild form of autism (Asperger, 1944). In contrast to the youths Kanner described, Asperger's children possessed a high level of intelligence and displayed no signs of cognitive or communicative delays in their development. Asperger reported that his subjects

exhibited areas of intense interest, typically academic in nature (e.g., astronomy), and would speak about these topics for hours on end. Due to their extensive knowledge of, and dedication to, a particular field, Asperger referred to his subjects as "little professors" (Asperger). Similar to Kanner's observations, Asperger noted that his children showed an intense aversion to change, clumsy motor movements, and an overwhelming desire to remain alone. In 1981, British psychiatrist Lorna Wing coined the term "Asperger's syndrome" to distinguish Asperger's findings from Kanner's early infantile autism. Wing argued that an AS diagnosis would help to explain the behavior of individuals who displayed autistic characteristics, but showed no verbal or cognitive delay and an increased social competence (Wing, 1981). The DSM-IV added AS to the list of PDDs, along with autistic disorder (AD), an updated and lifelong version of Kanner's autism (American Psychiatric Association, 2000). Approximately twenty years later, the DSM-5 replaced the individual diagnoses of AS and AD, along with childhood disintegrative disorder (CDD) and pervasive developmental disorder not otherwise specified (PDD-NOS), with the "umbrella diagnosis" of autism spectrum disorder (ASD). ASD retained the diagnostic criteria for each eliminated disorder, but placed affected individuals on a continuum of functioning and associated characteristics (American Psychiatric Association, 2013).

An Autism Identity

The DSM-5 review committees' decision to merge the majority of pervasive developmental disorders (PDDs) into the "umbrella diagnosis" of autism spectrum disorder (ASD) sparked heated debate in the autism and scientific communities. In particular, many individuals with Asperger's syndrome (AS) expressed feeling robbed of a part of their identity (Parsloe & Babrow, 2015; Solomon, 2017). Under the DSM-IV's diagnostic criteria, psychiatric

professionals examined deficits in social interaction and language development separately. The presence of a cognitive or communicative delay in development provided an important diagnostic distinction between AS and autistic disorder (American Psychiatric Association, 2004). When the DSM combined social interaction and communication, it removed the primary diagnostic difference between these two disorders (Solomon). The DSM-5 segments ASD into three levels of functioning: high, moderate, and low. Under the new system, the levels of functioning roughly correlate to one of the removed disorders. For example, an individual with "high-functioning" autism (HFA) would likely have received a diagnosis of AS prior to the transition (Solomon). Individuals with HFA typically experience minimal interference in their daily lives. They tend to attend higher institutions of learning and hold down jobs that contribute to society (e.g., Temple Grandin or Alan Turing). In contrast, people with "low-functioning" autism (LFA) require additional assistance in executing their routine. These individuals can still hold successful careers, but will likely require the presence of a guardian for the majority of their lives (Solomon).

According to Heather J. Carmack (2014), Asperger's syndrome (AS) provided people with two drastically different forms of identity: tertiary and social. A tertiary identity refers to an individual's medical diagnosis. Physicians use tertiary identities to categorize people who display abnormal characteristics. The DSM-5 elected to remove AS and AD due to questions about their validity as distinct tertiary identities. Using the DSM-IV's criteria, researchers presented several children with AS at an autism conference with an autism checklist. 20 out of the 26 examined children met the criteria for AD rather than AS, indicating issues with the current diagnostic process or criteria (Tryon, Mayes, Rhodes, & Waldo, 2006). In contrast, a

social identity provides an individual with a sense of community and belonging. For many people with AS, their diagnosis offered them a unique social identity where they could develop new relationships through shared experiences and challenge the definition of "normal" (Carmack, 2014). One such online AS community, Wrong Planet, contains over 80 thousand members. Parsloe and Babrow (2015) searched Wrong Planet's online message boards to learn more about the AS community's perception of the DSM-5's changes. Many individuals expressed a fear of losing their diagnosis and, as a result, their AS community. Several members shared "masking stories," tales of their adopted coping mechanisms to downplay AS traits. A common concern among these individuals was the possibility of a clinician removing their diagnosis due to their inability to "perform autism." One commenter shared their concerns over losing their autism as a social identity: "To most people, even psychologists, I appear to be a neurotypical. I'm not though. I still have ASD. I have just learned to "ignore" it. That is ... why they would play with the idea of "outgrowing" ASD. It's not possible. ... It's who you are." (Parsloe & Babrow, 2015, p. 488). For many individuals on Wrong Planet, an AS diagnosis provided a positive explanation, rather than a stigmatized label, for their behaviors. The explanatory power of an autism diagnosis extends beyond the primarily affected individuals. Brosnan and Mills (2016) conducted an experiment to measure the responses of college students to diagnostic labels. 120 students in the United Kingdom were presented with a scenario where an individual displayed autism-associated characteristics. The subjects in the control condition received no additional information. However, in the experimental conditions, participants were given an explanatory diagnosis of autism or schizophrenia. Using a Positive and Negative Affect Scale to measure responses, researchers discovered that the presence of a diagnostic label

increased the participants' positive perception of the individual described. No difference between diagnostic labels was recorded (Brosnan & Mills, 2016). Many individuals with autism attend college and may experience a dilemma over whether or not to disclose their diagnosis to the university or their peers. Brosnan and Mills' findings indicate that disclosing a diagnosis can have significant social benefits.

In *On the Appearance and Disappearance of Asperger's Syndrome*, Miriam Solomon makes an important point about the downside of an Asperger's diagnosis. Many individuals with AS have developed their positive social identity by engaging in downward social comparison with individuals with LFA. Michael Scott Monje Jr. perfectly describes this behavior: "the term "Aspie" has come to be a way for those of us who want to talk about our experiences to separate ourselves from "those" Autistics. It allows us an identity that has been sanitized for our allistic audience--a way of performing eccentricity instead of disability, of showing we are "like them" but "still employable." (Solomon, 2017, p. 183). While Solomon raises good points, the new diagnostic system does not solve the problem of downward social comparison. In fact, it encourages it. Specifying an individual's diagnosis as "high-functioning" indicates that someone "low-functioning" exists. The DSM-5 did not improve the negative "identity politics" associated with AS.

Autism in Popular Culture

The depiction of autism in popular culture and social media can have a constructive or devastating impact on an individual's identity and feelings of self-worth. The last several years have seen a dramatic shift in the portrayal of autism in television and film. Rather than characterizing a disorder for story or comic relief purposes, the media now showcases the

everyday experiences of individuals living with autism. For example, the Netflix original series *Atypical*, provides a unique perspective into the dating life of an individual placing on the autism spectrum. The primary character, Sam, documents his experiences navigating the complex social world of high school. Sam demonstrates an intense interest in arctic penguins and lists off each species when overwhelmed. In addition, he shows hyper reactivity to sensory input and wears noise-cancelling headphones to school. *Atypical* also depicts the experiences of Sam's family. His mother attends an autism support group for parents, and his sister gives up social opportunities to take care of him.

In the realm of literature, Mark Haddon's *The Curious Incident of the Dog in the Night-Time* beautifully chronicles the adventures of a youth with autism. Haddon provides the reader with wonderful examples of a developing sense of empathy and Theory of Mind (ToM). The primary character, Christopher, writes his thoughts and behaviors in a journal. He has an affinity for prime numbers and despises the color yellow. Another excellent book intended to educate people about AS, *All Cats Have Asperger Syndrome* (2007) provides a humorous analysis of autism-associated characteristics. Similar to cats, individuals with AS do not like being touched unless they initiate contact and may talk, or meow, for hours about topics of interest.

Associated Attitudes, Emotions, and Behaviors

Autism features a highly diverse constellation of associated phenotypes. ASD presents in varying degrees of severity, ranging from "low-functioning" to "high-functioning" autism (Solomon, 2017). Although two people might share an autism diagnosis, they may have minimal to no overlap in their behaviors or experiences. The DSM-5 contains a detailed outline of the

behaviors physicians use to diagnose autism spectrum disorder (ASD). However, the DSM does not provide information about the subjective attitudes and emotions frequently experienced by individuals with ASD. To enhance the descriptions found in the DSM-5, and to illustrate a comprehensive portrait of the broader autism phenotype, I will include personal viewpoints, stories, and examples. The DSM-5 divides the diagnostic criteria of ASD into two categories: persistent deficits in social interaction and communication, and the presence of restrictive, repetitive patterns of interests or behaviors (RRIBs) (American Psychiatric Association, 2013).

Persistent Deficits in Social Communication and Social Interaction

The first category examines deficits in three important areas for socialization and communication: social-emotional reciprocity, nonverbal communicative behaviors, and the developing, maintaining, and understanding of relationships (American Psychiatric Association, 2013). Examples of deficits in social-emotional reciprocity include an inability to engage in dynamic conversations, reduced sharing of emotions or interests, and a failure to respond to, or initiate, social interactions (American Psychiatric Association). Like many individuals with autism, I struggle to participate in back-and-forth conversations featuring changing topics. I tend to become fixated on a particular subject of interest and will continuously share, or blurt out, information until I have nothing left to say. At other times, I find myself easily distracted and unable to concentrate on the present discussion. My parents claim that I have "selective hearing," and that I stop listening to them once I hear information that I find interesting or upsetting. I also strongly dislike sharing information about my emotions or interests. I view this as similar to someone feeling uncomfortable looking at old photographs or hearing the sound of their own voice. When people ask me about my day, I tend to respond in automatic phrases (e.g., "doing

well, how are you?") or groans. I have a tendency to attribute information that only I possess to others, particularly my parents. When they ask about my day, I typically think about my response, but do not answer.

Deficits in nonverbal communicative behaviors include abnormalities in eye contact, difficulty reading body language, and the absence of facial expressions (American Psychiatric Association). I feel incredibly uncomfortable when making eye contact with other people. It feels unnatural and every instinct that I have tells me to look away. However, I recognize the importance of looking at people's faces during social interaction, and I often force myself to maintain eye contact for as long as possible. My lack of facial expressions led to a rather humorous encounter in high school. After reading Jonathan Swift's' *A Modest Proposal*, I wrote a satirical speech promoting the relocation of anyone over the age of 50 to Alaska. I made outrageous claims and provided fake statistics to support my argument. Apparently, my facial expression remained the same throughout the presentation and no one could tell if I was joking. One of my classmates approached me after my speech and asked me why I wanted to take away her grandmother.

Deficits in developing, maintaining, and understanding relationships include difficulties adjusting behaviors and engaging in imaginative play with others (American Psychiatric Association). During my childhood and adolescence, I struggled to change my behaviors when interacting with different groups. I possessed a very adult-like sense of humor and I would often make comments that upset my friends. In addition, I would occasionally behave in an inappropriate or juvenile manner around adults. For example, during a fire drill at my elementary school, I burst out laughing after someone made a joke. The joke had occurred approximately

five minutes before my reaction, but I could not stop thinking about it. The principal reprimanded me for my disturbance, but I struggled to figure out what I had done wrong. I also experienced difficulty when playing with others. I preferred to interact with physical objects, such as comic books or action figures, over other people. However, I would engage in imaginative play with others on occasion. For my participation in a game, I typically required complete control over the activity. My parents described my play as having "levels," similar to a video game. I appreciated order and would enforce strict rules on my peers. My inability to relinquish, or share, control often led to conflict with my friends.

Restrictive, Repetitive Patterns of Interests or Behaviors

Individuals with autism spectrum disorder (ASD) demonstrate restrictive, repetitive patterns of interests or behaviors (RRIBs) in several areas: motor movements, adaptability, fixated attention to specific topics, and sensitivity to stimuli (American Psychiatric Association, 2013). During my childhood, I displayed significant impairment in my fine motor skills. I could not tie my shoes until the fourth grade, and I refused to participate in any activities involving running or balls. I lacked the necessary coordination, and ambition, to play instruments or sports. In addition, I would repetitively line up toys or objects. I had a small collection of animal figures that I would take with me to public places and arrange in an orderly manner.

Throughout my youth, I demonstrated an intense aversion to change. I hated unpredictability. For example, I would growl at my mother whenever she attempted to rearrange the furniture in my playroom. I also consumed the same lunch every day for thirteen years. My diet has expanded and I am no longer horrified by unexpected deviations in routine. The topics that captured my attention included Star Wars and other fantasy universes. I appreciated the

break from reality. I would watch movies, or read books, and create detailed diagrams and lists of major characters and plot points. I also demonstrated a hyper-reactivity to certain stimuli. For example, I experienced tactile sensitivity and refused to wear jeans due to their rough texture. I also disliked going out in public. The noise and large amount of people upset me and I felt overwhelmed. Due to my anxiety, I rarely ate a restaurant or went shopping. However, I enjoyed going to the movies. They provided an escape from reality and minimal social obligation.

Autism and Anxiety

In comparison to the "neurotypical" population, individuals with autism have an increased likelihood of receiving a diagnosis of anxiety (Muris, Sterrneman, Merckelbach, Holdrinet, & Meesters, 1998; Green & Ben-Sasson, 2010). In particular, previous research suggests that a positive correlation exists between sensory over responsibility (SOR), hyper-reactivity to environmental stimuli, and anxiety in individuals with autism (Green & Ben-Sasson). Correlational studies have revealed that approximately 18 to 87% of children with ASD also have a diagnosis of anxiety (Muris et al.; Green & Ben-Sasson). In contrast, the prevalence rate of anxiety in TD preadolescents fall between 3 and 24% (Cartwright-Hatton, McNicol, & Doubleday, 2016). Furthermore, 56-70% of individuals with ASD, and 10-17% of the general population, experience SOR (Cartwright-Hatton, McNicol, & Doubleday). While the reason behind this correlation remains unknown, researchers have developed several hypotheses. One such hypothesis states that high anxiety levels lead to SOR. Anxious individuals have a tendency to remain aroused and vigilant in unfamiliar or unpredictable environments. SOR might result from continuous environment scanning and threat preparation (Green & Ben-Sasson). Another theory proposes that SOR causes anxiety. An overreaction to certain stimuli may

condition a fear response. For example, someone with a fear of loud popping noises might be conditioned to fear balloons (Green & Ben-Sasson). The final hypothesis suggests that SOR and anxiety share an unknown causal factor. Previous research has indicated that abnormalities in the amygdala, the brain structure typically associated with the fight-or-flight response, contributes to anxiety disorders. Juranek et al. (2006) discovered that some children with ASD, who were rated by their parents as being highly anxious, have an increased amygdala volume in comparison to TD individuals (Juranek et al., 2006).

During my childhood, I had an intense fear of death. In particular, I worried profusely about losing those closest to me. When I felt stressed in public places, I would ask familiar people their age. Using that information, I would compile a "death list" of when each person was expected to die. I believe that these lists offered structure in an unpredictable environment and, pending their accuracy, ensured that I would not lose my parents without warning. The problem with my "goddamned death thing," as my maternal grandmother affectionately referred to it, was that I would inform people of their placement on my lists. Family gathering became very awkward when I told people the order in which I expected them to die.

Sex Differences in Autism

Autism features a male-to-female sex ratio of 4-5:1 (Werling, 2016). The reason behind this phenomenon remains unknown. Bernard Crespi (2008), an evolutionary biologist, proposes the idea that autism stems from the domination of male-associated genes during pregnancy. From an evolutionary perspective, males tend to show less empathy and social awareness than females (Crespi & Badcock, 2008). On the opposite end of the spectrum, Crespi suggests that disorders like schizophrenia might result from the success of female-associated genes (Crespi & Badcock,

2008). The typical behaviors associated with autism differ between sexes. For example, females with autism tend to display an increased social competency, and possess a greater desire for peer interaction in comparison to their male counterparts. In addition, females with autism demonstrate less eye-gaze aversion and spend more time looking at other people's faces (Whyte & Scherf, 2017). Females also tend to display restrictive interests relating to people or animals, rather than objects or things (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015).

Signs of Neurodiversity

During the 1960s, a popular belief emerged that "refrigerator parents," cruel or unaffectionate caregivers, contributed to autism-associated behaviors (Solomon, 2017). We now know that neglectful parenting does not "cause" autism. Instead, genetic and environmental factors work in tandem to produce autism characteristics (Talkowski, Minikel, & Gusella, 2014)[6] . Research has revealed that autism features a highly heritable genetic component. A meta-analysis of twin studies found that on average, monozygous twins have an increased likelihood of sharing an ASD diagnosis (64%) in comparison to dizygous twins (9%) (Talkowski, Minikel, & Gusella)[7]. The development of genome-sequencing technologies has significantly improved our ability to identify the biological mechanisms that influence specific mental "disorders." A genome refers to the entirety of an organism's genetic material. Using genome-wide surveys, researchers can examine a plethora of genetic factors, ranging from single nucleotide variants to chromosomal abnormalities (Talkowski, Minikel, & Gusella, 2014). For example, genome-wide association studies (GWAS), which seek to identify the genetic

[6] For more information about genome-sequencing, and the genetic underpinnings of autism, see Talkowski, Minikel, & Gusella (2014)

[7] Monozygous, or identical, twins originate from the same zygote, or sex cell. In contrast, dizygous, or fraternal, twins originate from separate zygotes.

foundation of targeted phenotypes, have discovered several new risk loci for schizophrenia (Ripke et al., 2011). Despite these methodological advancements, the genetic underpinnings of autism spectrum disorder (ASD) remain shrouded in mystery. Studies have revealed that no single "autism gene" exists. Instead, hundreds of mutations and variations contribute to autism-associated characteristics (Talkowski, Minikel, & Gusella). Autism's diverse genetic component makes it almost impossible to study. Previous studies on other neurodevelopmental disorders have indicated the potential influence of postzygotic mosaic mutations (PMMs). In an experiment conducted by Krupp et al. (2016), researchers applied whole-exome sequencing techniques to DNA from the Simons Simplex Collection (SSC)[8], a databank containing genetic material from individuals with autism and their families. The study found that PMMs only contribute to 3-4% of SSC cases (Krupp et al., 2016). Before generalizable conclusions may be drawn about autism genetics, further research is required.

Theory of Mind

A "Theory of Mind" (ToM) refers to an individual's ability to attribute complex cognitive and affective states to themself and to others (Pino et al., 2017). Playing an important role in everyday social interaction, a ToM allows an individual to comprehend the beliefs, intentions, and emotions of other people. Most typically developing (TD) children display evidence of a consolidated ToM at around four to five years of age (Pino et al.). In contrast, children with autism spectrum disorder (ASD) tend to experience a significant delay in their acquisition of a ToM (Baron-Cohen, Leslie, & Frith, 1985; Pedreño et al., 2017, Pino et al.). In a study conducted by psychologist Simon Baron-Cohen, youths with autism, down syndrome, and

[8] The Simons Simplex Collection (SSC) contains DNA from over 2,600 individuals with autism and their families. A "simplex" family features only one individuals with an autism diagnosis.

a control group of TD preschoolers were given a standardized false belief test. A false belief test presents a subject with new information that an actor in a hypothetical situation does not possess (e.g., the knowledge that a pencil case holds an eraser instead of a pencil). Someone with a fully developed ToM should recognize that the actor does not share their knowledge and predict their behavior accordingly. In Baron-Cohen's experiment, the participants were presented with two dolls, Sally and Anne, and their baskets. The researchers acted out a scene in which Sally finds a marble and places it in her basket. After making Sally leave the room, the experimenters had Anne move the marble into a different basket. The researchers then asked each participant where they believed that Sally would look for her marble upon her return. 23 out of the 27 TD preschoolers, and 12 of the 14 children with down syndrome, correctly guessed that Sally would search in her own basket. However, 16 of the 20 adolescents with autism failed the false belief test by predicting that Sally would look for her marble in Anne's basket. The individuals who failed the false belief test could not attribute the absence of specific knowledge (i.e., the location of the marble) to Sally. They proved unable to differentiate Sally's mind from their own (Baron-Cohen, Leslie, & Frith).

A ToM also contributes to an individual's mastery of language. An understanding of rhetorical devices, such as metaphor or hyperbole, requires insight into another person's mind (Brown, 2016). For example, someone without a fully developed ToM would likely interpret William Shakespeare's famous metaphor that "all the world's a stage" as literal (Shakespeare, 2016, p. 696). Of course, Shakespeare did not literally mean that the world is a wooden stage in a high school production of *Hamlet*. However, without the proper context or understanding, an individual misses Shakespeare's intended meaning. Brown (2016) argues that a ToM plays an

integral role in joke-work. Jokes require proper comedic timing and the ability to "know another person's mind." Children with autism have a very concrete view of the world. They understand facts and straightforward information, but similes and double-entendres get lost in translation (Brown, 2016). The substantial delay in the onset of a ToM experienced by people with ASD has led some psychologists to question whether these individuals ever develop empathy or if they qualify as moral agents, being capable of differentiating between right and wrong (Krahn & Fenton, 2009). In their analysis, Krahn and Fenton (2009) conclude that morality, similar to a ToM, exists at different levels. While an individual might have difficulty understanding the thoughts or emotions of others, they can still identify morally objectionable behaviors (Krahn & Fenton).

Similar to many children with ASD, I struggled with a Theory of Mind (ToM) during my early childhood and adolescence. I did not understand how my words or actions affected others, and I often made insensitive or inappropriate comments that landed me in trouble. For example, when my parents lectured me about eating good food to stay healthy, I made a rude remark about my aunt's weight. When I reflect on my youth, I feel guilty for having said and done things that offended others. I impulsively blurted out my thoughts, and I could not comprehend how someone else could feel sad or angry when I did not. From my experiences, I believe that an individual placing on the autism spectrum may develop a ToM over time. Years of forcing myself to examine situations from other people's viewpoints, or "placing myself in their shoes," has made me adept at resolving interpersonal conflict. In addition, I have become excellent at listening to other people's problems and proposing well-rounded solutions.

Assistive Measures

Everyone benefits from some form of assistance. In the same way that people with poor eyesight wear contacts or glasses to improve their vision, individuals with autism enhance their social and communicative skills through therapeutic measures. Due to its diverse constellation of associated behaviors and attitudes, autism does not have one standard form of treatment. Accepted methods of assistance range from animal-assisted intervention (AAI) to applied behavioral analysis (ABA). In a meta-analysis of studies featuring AAI, O'Haire (2012) found a significant improvement in the social interaction skills of subjects in 22 out of 28 experiments. AAI entails pairing an individual with autism with an animal, typically a horse or dog, for an hour a week over the course of several months. Psychologists believe that AAI fosters a desire for interpersonal interaction in individuals with autism by providing a low stress environment for socialization (O'Haire, 2012).

Studies involving musical therapy have resulted in significantly improved social interaction skills, and fine motor coordination, for participants with autism (Mössler et al., 2017). Individuals with autism tend to display a reduction in cerebellum volume (Stoodley et al., 2017). The cerebellum contributes to a person's motor coordination. Learning an instrument, or engaging in any activity that requires precise motor skills, can increase the size of an individual's cerebellum. Stoodley et al. (2017) managed to induce autistic characteristics (i.e., restrictive, repetitive patterns of interests or behaviors) by inhibiting activity in specific areas of the cerebellum (Stoodley et al.). Another popular form of autism therapy, applied behavioral analysis (ABA) promotes socially acceptable responses through positive or negative reinforcement. Children typically work one-on-one with a professional who guides them through various educational problems and scenarios. The development of new technologies, such as the

iPad, that can replace these professionals, has increased the incorporation of ABA in classroom settings (Nelson, 2014). Another staple for treating psychological disorders, cognitive-behavioral therapy promotes the use of coping mechanisms to remedy negative thoughts and behaviors (Cooper, Smith, & Russell, 2017). Having a positive perception of one's diagnosis can drastically improve an individual's self-esteem and lower rates of anxiety and depression. Many individuals with autism participate in support or therapy groups where they discuss their attitudes, emotions, and behaviors. Working through issues in a close community, individuals in support groups tend to develop a sense of belonging and a positive perception of their disorder (Cooper, Smith, & Russell).

Robert: 2018

Robert, also known as "Sam," is a 22-year old senior psychology major enrolled at DePauw University in Greencastle, Indiana. After his graduation in May, Sam intends to pursue a career in neuroscience or clinical psychology. His childhood experiences with mental disorders sparked his interest in these disciplines. Many of Sam's behaviors have changed significantly since his initial evaluation. For example, Sam demonstrates an increased social competence and a consolidated Theory of Mind (ToM). He enjoys participating in group activities and often acts as a confidant to his close friends. During the 2015-16 academic year, Sam held a position at his University as a First Year Resident Assistant, a job requiring a tremendous amount of social interaction and interpersonal communication. He no longer paces when stressed, but continues to meticulously comb through his work and make lists. Sam questions if he still qualifies for a diagnosis of Asperger's syndrome (AS) or autism spectrum disorder (ASD). Based upon the criteria found in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*

(DSM-5), Sam no longer experiences severe deficits in social communication and interaction. However, he still struggles with restrictive, repetitive patterns of interests or behaviors (RRIBs). Sam wonders how many people "outgrow" the behaviors associated with their disorders. He argues that when a diagnosis is given, the diagnosing physician takes a snapshot of that individual's life and applies that image to their future. While disorders may remain lifelong as a social identity, they are not necessarily a permanent tertiary identity.

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