Audience Analysis

This paper is directed towards anyone who is invested in continuing the study of autism. It could be particularly helpful to parents and guardians of children with autism who are looking for viable treatments that are both safe and effective. College students majoring in Special Education, Behavioral and Community Health, or Neurobiology, as well as their professors, may use this paper to gain a greater understanding of autism. This essay may be found in a report on the 2009 Autism Speaks Walk and in response to general protests against autism research. It could also be used as a marketing tool to solicit donations for trustworthy autism research. However, the fiscal standing of the target audience is irrelevant. It is most important that the audience care about making the safest, most effective choice for treating those with autism. My hope is that this paper will inspire research that advocates for the safe, scientifically proven treatment of autism spectrum disorders. I understand the opposition facing autism research first-hand and realize that a lack of immediate results in tracking the causes and cures of autism can be discouraging. As a special education major at the University of Maryland, autism research greatly interests me and will impact my future students and their families.
Addressing Autism

Autism is a complex neurodevelopment disorder that has confounded some of the most experienced medical researchers in the world (Nadesan 9). Its causes and ideal treatments remain unknown while the prevalence of autism radically increases. In the 1970s an average of three people in every ten thousand of the global population were believed to have an autism spectrum disorder (B. Williams and R. Williams 17). Currently, the most recent prevalence rate “stands at 100 per 10,000” people—an astonishing rise in a mere forty year margin (B. Williams and R. Williams 17). Professionals in the medical world have declared this increase in autism, particularly childhood autism, a worldwide epidemic (B. Williams and R. Williams 17). In America alone, “as many as 673,000 [youth] age 21 or under cope with an autism spectrum disorder” (B. Williams and R. Williams 17). The multifariousness of autism spectrum disorders has prevented researchers from producing game-changing findings. Increased funding for autism research and the expansion of associate autism awareness campaigns must occur in order to heighten the public’s knowledge of autism and address other urgent autism quandaries.

In 1943, Leo Kanner, a forefather of child psychiatry, deemed those who exhibited both social and communicative impairments as having a condition he called infantile autism (B. Williams and R. Williams 4). Kanner included the term infantile to highlight the early onset of this condition. According to coauthors Betty F. Williams, a coordinator of the Special Education program at Whitworth University, and Randy L. Williams, a professor in the Department of Special Education at Gonzaga University, autism is derived from “the Greek work autos, meaning self, and was intended to describe an extreme withdrawal of oneself from one’s social surroundings” (B. Williams and R. Williams 4). The symptoms that Kanner recognized in these children are still used as the primary indicators of autism. Atypical behaviors such as
indifference to social engagement, inability to understand social cues, and lack of empathy all lead to undeveloped social and communication skills. Unfortunately, this barrier of incomprehension often leads to “self-stimulation, stereotypy, self-injury, and aggression” in individuals with autism (B. Williams and R. Williams xvii). This is not to say that children with autism are less intelligent than neurotypical children, but rather those with autism lack the ability to communicate their underlying intelligence.

The apparent intelligence and lack of physical deformity led Kanner to question his original belief that “the disorder had a neuropathological origin” (B. Williams and R. Williams 5). Instead, the popular psychoanalytic theories of Sigmund Freud influenced Kanner’s perception of autism. Freudian ideologies swayed Kanner to suggest that “autism [is] caused by being reared by cold, detached humorless, rigid parents who [are] perfectionists and [raise] their children mechanically” (B. Williams and R. Williams 5). Kanner’s psychoanalytic theory that blamed “refrigerator moms” for childhood autism went unquestioned until the 1960s. However, before the theory was debunked, it caused considerable harm to the autistic community and their families.¹ Not only did this theory place unbearable levels of guilt on the mothers of children with autism, it hindered the advancement of autism research. Kanner’s “refrigerator mom” theory “distracted researchers from serious biomedical research to determine if neurological conditions contributed to the development of autism” (B. Williams and R. Williams 5). Unfortunately, trying to reestablish the importance of biomedical research on autism has proved difficult. In the 1960s, parents who refused to accept Kanner’s theory turned to research being conducted on neurobiological explanations. When researchers Bernard Rimland, founder of the

¹ I recognize that the use of the word “autistic” can be offensive to some people because it labels individuals with autism as part of a disability group. It is not my intention to offend anyone. For the purpose of this paper, I use the word autistic to merely inform my audience in the clearest manner possible. I fully support the use of Person First Language and believe that we should always strive to focus on the person at hand rather than their disability.
Autism Society of America and editor of the journal *Autism Research Review International*, and Michael Rutter, of the Institute of Psychiatry, independently applied the scientific method to Kanner’s theory of maternal blame, they were able to establish that “the parents of children with autism [raise] their children no differently than other parents” (B. Williams and R. Williams 5). Scientific research methods successfully disproved the most detrimental theory in autism history.

This kind of success has led me to believe that scientific research is a necessary component in understanding autism. There have been many attempts at understanding autism, including Lorna Wing’s autism spectrum, which is frequently used in discussing autism diagnoses and treatments. Although Asperger’s syndrome has sometimes been treated as a variation of autism as a result of Lorna Wing’s 1991 essay “The relationship between Asperger’s syndrome and Kanner’s autism,” for the purpose of this essay, I am going to focus solely on autism itself (Nadesan 13).

In this essay I will argue for an increase in scientifically supported research on autism. By first explaining that autism is biologically fueled as opposed to psychologically generated, I will give reason as to why we should pursue biomedical research on autism. Additionally, I will present various evidence of the harms caused to individuals with autism by faulty treatments and the symptoms of autism itself. After describing the detrimental aspects of all three diagnostic categories, I will confront the claims of my opposition. By recognizing and refuting the aims of the Neurodiversity Movement, I will debunk all reasonable opposition to my argument. Lastly, I will reaffirm my belief that biomedical research is the only way to find a treatment that will prevent or ameliorate the effects of autism.

Preliminary evidence that autism is a biologically based disorder has already been discovered in the world of medical research. In June 2010, researchers “found rare, novel genetic
variations in children with autism” (Shute 6). Although each individual was found to have a different genetic mutation, there is clear evidence that the deficiencies were all within the “genes that control communication” (Shute 6). In Constructing Autism, author Majia Holmer Nadesan acknowledges the recent value placed on scientific research. She states,

Given such clear evidence that biogenetic factors are implicated in the disorder, much recent research focuses on identifying the specific genes causing the complex array of symptoms whose constellation enable a diagnosis of autism. (147)

This focus on specific gene identification has been further encouraged by the discovery of high rates of autism in identical twins, a common psychological tool used to determine the role of genetics in developmental disorders (Nadesan 147). There is no doubt that a child with autism’s lack of communicative ability is biologically fueled. Given that the medical community has traced autism to a neurological difference, further scientific research can and should be done to develop an effective treatment for autism.

Although a reliable treatment remains undiscovered, many parents turn to expensive and dangerous alternative therapies to alleviate the suffering that autism may be causing their child. For years, desperate parents have resorted to unregulated, expensive, and sometimes even harmful alternative treatments. However, as Nancy Shute proves in “Desperate for an Autism Cure,” turning to dangerous, unreliable remedies is not the answer to overcoming autism. The unproven therapies that parents often succumb to include: nutritional supplements, restricted diet, stem cell injections, self-help instructional videos and books, the use of a pressurized hyperbaric oxygen chamber, and untested drug therapies (Shute 4). Shute goes into detail about what these fraudulent remedies entail and why they need to be monitored and publicized. Adding to Shute’s argument, I would point out that it is crucial to the health of people with autism that the Food and Drug Administration take steps to warn parents about these experimental treatments and inform them of the potentially detrimental and even deadly effects.
In 2005, “a five-year-old boy in Pennsylvania with autism died after being given intravenous chelation” (Shute 4). Chelation, the process of extracting heavy metals from one’s body, became highly popular when the unproven theory that exposure to methylmercury from vaccine preservatives was the cause autism in young children (Shute 4). After numerous studies done on this highly sensationalized vaccine-theory, medical professionals have come to the conclusion that vaccines do not play a casual role in the diagnosis of autism in young children (Shute 4). However, Shute still stresses that the once popular alternative treatment of chelation “can cause kidney failure, particularly in the intravenous form favored for autism,” since parents continue to turn to disproven treatments (Shute 4). The discovery of a viable treatment would shut down these dangerous practices and prevent any future harm to these innocent children with autism.

A medically approved treatment is necessary to replace these bogus interventions; however, research cannot be done without sufficient federal funding. In the past, the complexity of autism has often discouraged medical professionals from pursuing research in this area. Attempts to carry out scientifically valid, clinical trials are often shut down because they pose “more than a minimal risk” to the subjects of the study (Shute 4). This leaves only the field of social sciences and special education to conduct autism research. These two disciplines are dedicated but their lack of research budgets and protocol credibility has contributed to a failure to produce any real “evidence” (Shute 5). The lack of reliable medical research has had extremely serious consequences for autistic children and their families.

It is not just alternative autism treatments that put children with autism in harms way; often it is autism itself. Just as Leo Kanner described, symptoms of autism relate back to a lack of communication and social interaction skills (B. Williams and R. Williams xvii). According to
Jennifer Harrison Elder, Professor and Associate Dean for Research of the College of Nursing at the University of Florida, and Tina D’Alessandro, an Advanced Registered Nurse Practitioner, there are three diagnostic categories for autism: delays in speech and language, impaired social relatedness, and unusual and/or restricted behaviors/routines (Elder and D’Alessandro 241). The implications of these diagnostic behaviors are detrimental and sometimes even hazardous to the wellbeing of individuals with autism.

The first category, delays in speech and language, includes actions of Echolalia (also known as ‘scripting’), severe difficulty with language acquisition, using words nonsensically, or speaking in a sing-songy or monotone voice (Elder and D’Alessandro 241). Such speech disabilities are by far some of the most debilitating behaviors of autism. The Williams authors believe that “about half of persons with [an autism spectrum disorder] have little or no language, [and] about 75 percent are classified as mentally retarded” (7). Although people with autism are often some of the most intelligent individuals in the society, they are not able to demonstrate their intelligence without proper treatment. If there were a viable treatment and a suitable IQ test, the potential of people with autism would be common knowledge to all of society. Traditionally, there has been a link between autism and low IQ scores as demonstrated in the works of Betty and Randy Williams. However, David Wolman proves that this association may be misdirected by citing the extensive research of Michelle Dawson, a highly acclaimed cognitive researcher who has autism. Dawson’s findings call into question the widely accepted theory that people with autism are intellectually disabled. In 2007, Dawson and her research partner Laurent Mottron, head of the autism research program at the University of Montreal, “published a study showing that an autistic person’s IQ score depends on which kind of test is used” (Wolman 3). Dawson’s research further debunked the low IQ myth:
the most common test, the Weschsler Intelligence Scale, three-quarters of people with autism score 70 or lower which classifies them as mentally retarded. But when the team administered a different yet equally valid, IQ test known as the Raven’s Progressive Matrices, which places less weight on social knowledge, most people with autism scored at a level that lifted them out of this range. (Wolman 3)

It is undeniable that some with autism are fully capable in areas of expertise requiring academic intelligence; however, it is necessary to provide children with autism the necessary treatments that would allow them to be able to sit down and take a test.

The second of Elder and D’Alessandro’s diagnostic groups is the presence of impaired social relatedness. People with autism are well known for their lack of empathy that often leads to what the neurotypical society would consider blatantly rude comments. Poor eye contact and a general indifference to, or avoidance of, social contact also contribute to the socially awkward interactions those with autism often experience (Elder and D’Alessandro 241). Treatments that focus on the socialization of people with autism often help to lessen the exclusion that people with autism face from their neurotypical peers. As important as it is to accept people for who they are, it is undeniable that being ostracized will not help with one’s success in life. Current behavioral treatments for autism need to be researched and understood from medical perspectives in order to increase their effectiveness of integrating people with autism into the neurotypical world they live in.

Last, but not least of the areas of autism study that must be explored, is the diagnostic category of “Unusual and/or restricted behaviors/routines” defined by Elder and D’Alessandro (241). These abnormal behaviors warrant further research on applied behavioral therapy in addition to research concerning medical therapies. Individuals with autism tend to need rigid, highly structured routines, and if these set routines are changed, serious distress to those individuals will follow. Another behavior that prevents a person with autism from being productive in daily life is the tendency to exhibit “repetitive body movements including pacing,
hand-flapping, finger-flicking, spinning, rocking, and hitting oneself” (Elder and D’Alessandro 241). In addition to inflicting harm on oneself, these other examples of behaviors have the potential to escalate to an injurious level. “Apparent insensitivity to pain or temperature” along with “impulsive behavior and limited safety awareness” can put an individual with autism in very dangerous situations (Elder and D’Alessandro 241).

In order to combat a person with autism’s susceptibility to danger, certain behavioral therapies can be implemented. Applied Behavior Analysis is a behavioral therapy treatment that has been proven to increase the abilities of individuals with autism. Charlotte Brownlow, of The Open University’s Centre for Childhood Development and Learning, has said that Applied Behavior Analysis (ABA) is “the most ‘scientifically proven’ treatment for autism” even though it is a behavioral therapy rather than a biological treatment (1). The key to successful behavioral therapy is to start it as soon as possible. Those who receive early intervention, which preferably starts at an extremely young age, have proven not only to have improved IQ scores but also have significantly improved social skills. Controversies over ABA involve concerns that therapists will inflict a negative view of autism onto the child. Parents may worry that by having their child participate in therapy, the child will be predisposed to the idea that autism is a detrimental condition. I believe that there is a very feasible way to address this problem so that autistic children do not feel ostracized by professionals or even parents. Educating our culture, particularly therapists, about the effects of referring to autism with a negative tone and the importance of using positive terminology while discussing differences, could result in a major shift in how autism is perceived. By emphasizing progressive counseling techniques such as finding alternatives to unwanted behaviors as opposed to trying to eradicate them all together, the neurotypical community will become more welcoming to autistic behavior. This model of
cooperation will allow individuals with autism not only to satisfy their impulses but also to function as comfortably as possible in everyday society. Research on autism includes investigating all possible treatments, not merely biological treatments. Applied Behavioral Analysis has been proven to be a relatively effective treatment and, with more research, developing an extensive behavioral therapy program would be feasible.

Unfortunately, some people in the autism community do not support ABA therapy. In fact, some people believe autism should not be researched or treated at all. I first encountered opposition to my argument in 2009 at the national “Walk Now for Autism Speaks” rally. There I experienced first-hand the passion of both those who are dedicated to finding a cure to autism and those who are fiercely against the search for a cure. Sharing such a momentous event on the Smithsonian Mall with the autism community made me feel like I was part of something much larger than myself. As I walked alongside parents, siblings and even grandparents who were proudly holding the hand of an autistic loved one, I appreciated the enormous impact autism has had on many non-autistic lives. Knowing several individuals with autism has allowed me to understand the importance of speaking for those who cannot. We eagerly took our collective first steps, walking for a better future, and that was when I saw them—angry protestors against the search for a cure. The walkers’ positive attitude was reduced to feelings of confusion and anger. I was bewildered as the protestors held up signs with statements such as “I can speak for myself.” It was not just the furious protestors, but the similarly outraged rally participants, that added to my concern about the conflict within the autism community.

My experience at the Autism Speaks rally was just a glimpse of the discord among parents, teachers, and professionals invested in helping autistic individuals. They are all conflicted by how to address the growing issue of autism. Those who oppose a medically researched cure
believe that autism is not a disability but rather a form of individuality. These opponents believe that autistic people are just quirky characters who bring diverse personalities to society. I agree that the varying differences among those with autism should be accepted and recognized as contributions to society. However, I also believe that many of those who oppose a scientifically investigated cure, such as those protesting on that chilling day in October, are higher functioning autistics who disregard the need to help more severely affected individuals. In her submission to the *Journal of Intellectual & Developmental Disability*, Charlotte Brownlow points out that high functioning autistics often lead a “neurologically typical” life (15). Neurologically typical is a common substitute for the insensitive term, “normal.” Those who are profoundly affected by autism lead anything but a normal life; severely disabled individuals are often not able to speak and will never be able to voice their opinions. Simply because some people exhibit very mild cases of autism does not mean that those whose lives are severely impaired do not deserve a well-tested, randomized, and scientifically investigated treatment.

However, others disagree with me. According to Celeste Biever, a reporter for *New Scientist*, members of the Neurodiversity Movement, also known as the Autism Rights Campaign, are “angry about the way [autism] is portrayed by some charities” (1). Those who are offended by the efforts of charities such as Autism Speaks are missing the point of their efforts. Autism Speaks does not aim to change the inherently unique people affected by autism; instead, it attempts to alleviate the undeniable challenges that people with autism face. Shute points out that private foundations including Autism Speaks contributed $79 million in 2008 (6). According to Autism Speaks, “about 27 percent of all funding is being spent on investigating treatments, 29 percent on causes, 24 percent on basic biology and 9 percent on diagnosis” (Shute 6). I believe that this type of funding will positively affect even those people with autism who object to
autism research. Increasing the public’s knowledge about autism and fostering an understanding of this mysterious condition is invaluable.

In his article “The Autism Rights Movement,” Andrew Solomon, a recipient of the Humanitarian Award of the Society of Biological Psychiatry and a lecturer in psychiatry at Weill Cornell Medical College of Cornell University, interviews Ari Ne’eman, President of the Autistic Self Advocacy Network, about his efforts as a leader of the neurodiversity movement. Ne’eman asserts that “society [needs] to change, not autistic people” (1). Ne’eman is right; society needs to come together to make a collective change concerning how autism is perceived. However, what Ne’eman fails to realize is that the best way to change society’s opinion is by presenting scientific findings to the public from a credible organization such as the National Institutes of Health. The reality of the matter is that until the public is offered substantial medically-supported conclusions about autism, it is very unlikely that they will be swayed against autism treatment and research.

In a desperate attempt to refute the treatment of autism, the opposition will sometimes cite the success of famous people with autism. One of the most famous autism-success cases is the case of Temple Grandin. What my opposition fails to realize is that, as a researcher herself, Grandin supports autism research. Temple Grandin, a PhD in animal science, is a college professor, best-selling author, and inventor of the squeeze machine (Temple Grandin). Her biopic, Temple Grandin, demonstrated that people with autism face many struggles growing up in a neurotypical world. Dr. Grandin faced constant opposition and ostracism as a young girl with autism. As the inventor of the squeeze machine, a device meant to “hug” those with autism who are hyper-sensitized to human touch, Grandin realizes that even the simplest treatments can help those with autism adjust to their surroundings. In regards to Applied Behavioral Therapy,
Grandin believes that a minimum of 20-hours of one-on-one teaching is most effective (Temple Grandin). Many successful people with autism have had intensive ABA therapy. Amy Harmon followed the life of one of these individuals in her New York Times article “Autistic and Seeking a Place in an Adult World.” Justin Canha is an extremely talented cartoonist with autism. His dream is to be “a famous animator-illustrator” (1). Justin received behavioral therapy through “intensive coaching in the workplace and community” which has allowed him to live as an independent adult. Without the extensive treatments Justin received for his autism, it is very likely he could have “[ended] up unemployed and isolated, living with [his] parents” (“Autistic and Seeking” 1). Based on the many success stories, it is clear that research into the causes and treatments of autism has provided outcomes that enhance the life of a person with autism rather than hinder it. This is why the continuation of a research is crucial in helping people with autism thrive in the neurologically typical world we live in.

Thankfully, both the federal government and the general public have recently recognized the serious consequences stemming from a lack of knowledge on autism. This has led to a significant fifteen percent increase in funding per year for autism research (Shute 7). More importantly, many private foundations, such as Autism Speaks, put all of their funds towards biomedical research. Although some individuals, like the protestors I encountered, believe that it is wrong to focus on medically-based research, I believe that sound scientific research into autism is the only logical course of action in the search to find an appropriate treatment. I am aware that research will take a number of years, but we must be patient and account for the time lost when autism was disregarded by the scientific community.

In 1999, autism was still considered “a profound and poorly understood developmental disorder” (B. Williams and R. Williams 7). The combination of little progress in the field of
biomedical research on autism and an exponential increase in autism diagnoses has resulted in a
desperate need for public attention. The large global increase in autism and the lack of
explanatory information behind the condition itself warrant the attention of not only the scientific
and medical communities but of the federal government. The necessity to discover “causal
factors and effective treatment” for autism has never been more crucial than it is in today’s
societal climate (B. Williams and R. Williams 18).
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