THE EVER-CHANGING SOCIAL PERCEPTION OF AUTISM SPECTRUM DISORDERS IN THE UNITED STATES

Danielle N. Martin

East Carolina University

Faculty Mentor: Dr. Michael Bassman

ABSTRACT

This paper aims to examine the comprehensive social perception of autism spectrum disorders (ASDs) within the United States today. In order to study the broad public view of those with ASDs, this study investigates the evolution of the syndrome in both sociological and scientific realms. By drawing on the scientific progression of the syndrome and the mixture of this research with concurrent social issues and media representations, this study infers why such a significant amount of stigmatization has become attached to those with ASDs and how these stigmatizations have varied throughout history. After studying this evolving social perception of ASDs in the United States, the writer details suggestions for the betterment of this awareness, including boosted and specified research efforts, increased collaboration within those experts in autism, and positive visibility of those with ASDs and their families. Overall, the writer suggests that public awareness has increased and thus negative stigmatization has decreased in recent years; however, there remains much to be done to increase general social understanding of ASDs.

Keywords: autism, autism spectrum disorders (ASDs), social perception, stigmatization

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"Autism is about having a pure heart and being very sensitive… It is about finding a way to survive in an overwhelming, confusing world… It is about developing differently, in a different pace and with different leaps."
-Trisha Van Berkel

The identification of autism, in both sociological and scientific terms, has experienced a drastic evolution since its original definition in the early 20th century. From its original designation by Leo Kanner (1943), public understanding of autism spectrum disorders (ASDs) has been shrouded in mystery and misperception. The basic core features of all ASDs include problems with basic socialization and communication, strange intonation and facial expressions, and intense preoccupations or repetitive behaviors; however, one important aspect of what makes autism so complex is the wide variation in expression of the disorder (Lord, 2011). When comparing individuals with the same autism diagnosis, one will undoubtedly encounter many different personalities, strengths and weaknesses. This wide variability between individuals diagnosed with autism, along with the lack of basic understanding of the general public, accounts for a significant amount of social stigma in our society today. Social stigma stemming from this lack of knowledge has been reported in varying degrees since the original formation of the diagnosis. Studies conducted over the past two centuries have shown perceived negative stigma from the view of both the autistic individual and the family or caretakers behind that individual. Concurrent with these studies on perceived stigma have also been studies on public knowledge, media representations and medical classifications. In order to understand the evolution of autism in both scientific and sociological terms, one must condense this vast amount of knowledge into one general public perception.

This body of work will aim to bring to light many of the social misconceptions tied to ASDs in the United States today, in an effort to boost understanding and evaluate the reasons for this stigmatization. Herein, the reader will find a detailed history of the scientific understanding of ASDs, ending with a description of what science now understands autism to be. Next, the reader will be introduced to current issues in social perception and the history behind this medical and social disconnect. Finally, the writer will conclude with personal suggestions.

Literature Review

Scientific Evolution

While the syndrome of autism was surely existent prior to its official characterization, it was not until 1912 that Swiss psychiatrist Eugen Bleuler first used the term “autistic” to describe social withdrawal observed in schizophrenic adults (Happé, 1995). In the 1912 issue of the *American Journal of Insanity*, Bleuler falsely described autism as another form of schizophrenia; however, his description of these individuals did somewhat mirror modern descriptions of individuals with an ASD (Syriopoulou-Deli, 2010). It was not until a 1943 edition of the journal *The Nervous Child* that child psychologist Leo Kanner presented his complete definition of autism as a unique disorder under his label of “early infantile autism.” Kanner’s 1943 paper, entitled “Autistic Disturbances of Affective Contact”, aimed to characterize a set of similarly-displayed features observed in a study of eleven children. In each of these children, Kanner detected strong cognitive ability with concurrent severe social interaction difficulties, limitations in spontaneity, belated echolalia, hypersensitivity to stimuli, excellent rote memory, and a difficulty processing or adapting to change manifesting in an obsession for sameness. In his later publications, Kanner would go on to say that he perceived only two of these observed features as necessary and sufficient for the diagnosis of autism: extreme isolation and obsession on the preservation of sameness. One specifically crucial discovery by Kanner was that of the autism spectrum, or the concept that autism varied significantly between and within diagnosed individuals. He noted in his samples that ASDs were manifested in extremely varying fashions between individuals, with no two individuals expressing identical developmental strengths and weaknesses. Kanner also described how autism as a condition continued to evolve throughout the lifetime of each individual (Happé, 1995). While Kanner was the first to describe autism as an independent disorder, it has been found subsequently that his definition was still limited and thus insufficient.

Following this definition by Kanner came a flood of new research on the autism spectrum. In 1944, only one year after the original definition of the disorder, Hans Asperger published his work on childhood “autistic psychopathy”; however, this work would not become well known until its translation into English in 1997 (Syriopoulou-Deli, 2010). In a fashion similar to Kanner, Asperger described severe social withdrawal, obsession with routine or sameness, and individualized interests which often became additional obsessions. In comparison to the previous subjects studied by Kanner, however, these new participants expressed significantly better socialization and communication skills. Asperger’s Syndrome—as the term was defined by Lorna Wing in 1981—could then be employed to describe those who existed on the high-performing end of the spectrum, and whose difficulties were less severe than those with the straight diagnosis of autism (Happé, 1995). Since its introduction, guidelines concerning an Asperger’s diagnosis have been constantly challenged, with correct categorization as the main point of consternation (Syriopoulou-Deli, 2010). With this further categorization of individuals, understanding of autism was made both more complete and more complex.

It was in later papers of 1956 and 1967 that prominent educator and psychiatrist Bruno Bettelheim, in an attempt to explain away the confusion enshrouding ASDs, introduced his "refrigerator mother" theory. This theory, which was discredited following later scientific study, hypothesized that autism in children was developed as a response to a dangerous and unloving environment created specifically by the child's mother. He described these children as "solipsistic as infants in their contact with reality," and in his view this condition was solely a psychological issue that could be reversed with intense therapy for both mother and child. This hypothesis was officially discredited after the medical field as a whole shifted from pure psychological review to more biologically-based psychological studies of autism; however, following this shift, society as a whole has continued to struggle with the concept of autism as a purely medical condition (Syriopoulou-Deli, 2010). Bettelheim's original studies introduced a great deal of misunderstanding into the public eye, as well as confusion about the causes and foundations of autism.

A significant increase in biologically-based studies attempting to find the genetic, neurological or environmental basis of autism was seen after this post-Bettelheim shift in the late 20th century; however, the uncertainty surrounding this biological basis caused a definite split in the scientific community of the time. The influential study by Folstein and Rutter, published in 1977, first introduced autism as a specifically genetically-based disorder. Following studies by Rutter and Schopler, published in 1986, looked further into the frequency of the fragile X syndrome in autistic individuals, which is an abnormality in the X chromosome that largely affects males. In 1987, Karandanos examined the idea that autism and mental deficiency were not synonymous, and are caused by different neuropathological issues. Discerning this biological basis, however, has always been difficult, as ASDs vary so significantly between individuals. Darby (1976) and Williams (1980) addressed the issue of secondary complications and were unable to provide a sufficient biological explanation (Syriopoulou-Deli, 2010). While the search for a biological basis of ASDs has continued on to the present, research findings are both convoluted and insufficient.

While the search for a sufficient biological explanation has yet to come to fruition, this multitude of studies has led to a better-accepted and more complete definition of ASDs. Increased understanding has encouraged a transition from perceiving those with autism as mentally ill or dangerous to viewing them as special-needs individuals. It is now generally understood in the scientific community that autism is not a medical issue that may be cured; rather, it is a disorder marked by display of certain social characteristics. The establishment of this strong research base has also helped to create a set of criteria for the diagnosis of autism. Through statistical-epidemiological research, Lorna Wing and Judith Gould (1979, 1996) defined the basis of autism as “an obvious divergence from the expected socially correct behavior, independent of their mental and cognitive status.” In an evolution from Kanner’s earlier statements, Wing and Gould also introduced the idea of an “autistic continuum” that remains the accepted theory (Syriopoulou-Deli, 2010). These ideas remain the basis for autism identification and diagnosis.

Through this body of study, the current criteria for the evaluation and diagnosis of autism have been detailed. Generally known as Wing’s triad of impairments, three fundamental impairments exist at different stages of development that are necessary and sufficient for an ASD diagnosis. These three impairments lie in the areas of social interaction, imagination and communication. It is extremely common for individuals to display some sort of repetitive behavior pattern in addition to these three impairments; however, this behavior is not necessary in order to classify an individual as autistic. It is now widely understood that each individual is affected differently by autism; some may experience learning disabilities, while approximately 10% develop savant skills in specific areas. Other secondary characteristics include language difficulties, issues with motor skills, abnormal physical development or function, inappropriate emotional reactions, and hypersensitivity to sensory stimuli. It is also common for autism to co-occur with a variety of other disorders including epilepsy, attention deficit disorder and Down syndrome (Bogdashina, 2006). At this time, there are two internationally-employed and standardized diagnostic tools: the *World Health Organization's International Classification of Diseases, 10th edition* (ICD-10) and the *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 5th edition* (DSM-V). These standardized diagnostic tools, in conjunction with an increased understanding of what autism is and is not, have allowed for significant recent progress in the autistic community; however, stigma toward these individuals in the United States has far from disappeared (Bogdashina, 2006).

Social Evolution

The steady scientific evolution of ASDs has been paralleled with a simultaneous evolution in social perception and stigmatization. Stigmatized persons, as defined in 2009 by Oren Shtayermman, are those "who possess a quality that others perceive as negative, unfavorable, or in some way unacceptable." Stigmatization of those with developmental disabilities has always been common, as it is human nature to judge those who are noticeably different, with severity of this judgment and stigmatization typically increasing with severity of the condition (Shtayermman, 2009). Since the original definition of ASDs, those on the spectrum and their families have been have been challenged by stereotypes. The numerous reasons for this associated stigma include the individualized nature of the syndrome, the associated different speech and actions, and the lack of understanding in its physical basis. This stigmatization is made worse due to the inability of many autistic individuals to express their thoughts or emotions to neurotypicals.

A dramatic evolution in social perception may be seen while studying the history of autism study in the United States; however, there exists a common thread of social challenges that have been reported by autistic individuals of all ages at all points in history. The most prominent of these common experiences is arguably the recognized extreme feelings of isolation extending from childhood to adulthood, with many individuals reporting increased feelings of isolation as they grew older due to increased self-awareness and installment of stigma in the minds of peers. The reactions to these feelings of isolation understandably vary widely between individuals, with some attempting to accept these feelings of loneliness and others attempting to improve relationships with their peers. Again, it may be seen that the amount of improvement on these existing relationships will vary significantly from case to case, depending on a wide range of factors such as environment, intensity of impairment, and personality of the autistic individual (Müller, Schuler, & Yates, 2008). These feelings of isolation are also intrinsically connected to the amount of stigmatization that an autistic individual receives from those in the surrounding environment. Studies have shown that sense of stigmatization felt by those with an ASD is directly linked to their self-esteem, as those who perceive a greater amount of stigmatization have lower self-esteem (Shtayermman, 2009). One suggestion for this relationship was presented by Martz in 2004, who hypothesized that those with developmental disabilities such as an ASD may internalize outside stigmas placed upon them by peers (Shtayermman, 2009).

Combating these feelings of isolation and stigmatization is an extremely difficult challenge for many on the spectrum, as they are also faced with a multitude of additional impairments which act as an unlimited source of personal challenges.

Subsets of autistic individuals have reported additional personal challenges including, but not limited to: difficulty initiating and maintaining communication, issues building relationships, and combating the preconceived notions of peers. Communication is, on a very basic level, an aspect of daily life that many neurotypical individuals take for granted; however, it is a point of constant consternation for those with an ASD. Difficulty initiating conversation is often reported as the most difficult aspect of communication, as autistic individuals often either lack the understanding of how to initiate conversation or the self-confidence to approach a communicative situation. Continuing communication after initiation is similarly difficult, as participating in unstructured dialogue and understanding the implicit meanings behind verbal messages can be extremely confusing. In addition to the basic lack of understanding, communicating is made more difficult when one includes the more subtle behaviors that are involved in communication as well. These subtle behaviors include facial expressions, hand gestures, and tone of voice (Müller, Schuler, & Yates, 2008). All of these factors together create an outline for conversation that is infinitely more complicated than it may seem to a neurotypical individual.

These feelings of isolation, intensified by the described communication barriers, create an understandable longing for intimacy in many autistic individuals; however, this intimacy is again difficult to build and maintain. While it is often the wish of an autistic individual to become more emotionally and physically connected with another person, the basic limits of his/her own tolerance for emotional probing and physical touch become a fundamental problem. Then, it may be understood that it becomes important to develop relationships that are fulfilling yet still leave a significant amount of personal space—both physically and emotionally (Müller, Schuler, & Yates, 2008). Through these results by autistic individuals, a sense of severe loneliness and struggle may be felt, because of this difficulty in emotional connection.

The intensity of these social challenges, both individually and holistically, is determined in a large part by the environment and individuals that an autistic individual encounters on a daily basis. In considering what creates this complete and immersive social environment, one must consider the understanding of ASDs that permeates throughout that environment and the preconceived notions or stigmatizations that combat comprehension of new education or research. All of these factors together create a social perception of autism that is undeniably community-based yet varies widely between individuals. In order to understand the current social perception of ASDs in the United States as a whole, one must first examine the history and evolution of autism-based stigma.

The association of negative stigmatization with ASDs began with Eugene Bleuler's use of the word "autistic" to describe social withdrawal in schizophrenic patients. This original terminology assigned a decidedly negative connotation to the word. Re-use of the term by Kanner and Asperger roughly thirty years later to describe a completely new syndrome encouraged this negative connotation to transfer more generally to all of those individuals with an ASD. Introducing this new syndrome as almost an outcropping of schizophrenia, a disorder that is so negatively perceived in the public eye, set those with autism at an immediate social disadvantage. A large dose of public intrigue was added with the subsequent confusion concerning nearly every aspect of ASDs. Together, these two factors have provided a basis for public confusion and creation of an overall negative social perception of autism.

Following the original classification of autism as an individual disorder by Kanner in his landmark paper of 1943, a wide range of theories concerning the basis of autism were expressed. Initial research was based in the field of psychology, and focused specifically on identifying the basic cause of the syndrome in order to isolate means of prevention, early identification, and continuing treatment (Syriopoulou-Deli, 2010). As the condition was initially considered to be founded in the psychological rather than physical realm, it can be understood that Bruno Bettelheim was the first individual to propose a possible basis for the syndrome. Bettelheim introduced the psychogenic myth, which suggested that the "refrigerator mother" was the cause of autism. His refrigerator mother theory suggested that autism in children was simply a maladaptive response to a hostile and unloving environment created by the child's parents, with more emphasis placed on the parenting styles of the mother. In Bettelheim's view, the mother was herself in need of severe psychological treatment, and in many cases the child was removed from the mother's care. While this theory has since been discredited, the ideals associated with the psychogenic myth remain a challenge to the families of autistic individuals today. In addition, it may be seen in parts of Europe that this belief holds precedence over more recent scientific advances (Happé, 1995). It may be initially difficult to understand how this suggestion could be so widely accepted in the scientific and public realms; however, when one considers the social challenges of the time, it is much more easily understood. At this point in history, the United States was in an extreme transition point following World War II. During this time, women in some regions were integrated into the work force for the first time in United States history, and this shift was cause for strong opposition by more conservative individuals (Syriopoulou-Deli, 2010). This opposition made acceptance of the refrigerator mother theory more understandable. Here, one may witness the first example of how broad social perception of autism in the United States was undeniably influenced by the environment of the time.

In following years, a shift from Bettelheim's refrigerator mother theory was seen along with a simultaneous shift in the scientific realm as a whole. During this time, the study of autism progressed from a hypothetically psychologically-based syndrome to one with a both biological and environmental basis. Since the mid-twentieth century, a significant increase in these biologically-based studies has been observed; however, doubts remained that autism could be considered solely biologically-based. The search for a biological basis has become seemingly more convoluted over time and remains to be elucidated. Simply identifying the condition was difficult in itself, as there are significant variations between the type and intensity of impairments in autistic individuals (Syriopoulou-Deli, 2010). This continuing amount of doubt, paired with the inability of the scientific community to define a biological basis for the condition, has fueled a significant amount of media attention and public bewilderment.

Media portrayal of ASDs is an extremely important facet to consider when attempting to define public perception of those with autism. The original media tropes created during the time of Bettelheim's dominance have persisted despite the increase in overall understanding. This shift is due to the persistent flux of media attention that is largely created by people who are themselves neurotypical. According to the 2011 study by Sarrett, media attention throughout the years has consistently focused on the fragmentation and imprisonment of autistic individuals, specifically autistic children. These themes have worked to introduce an additional level of mystery into the public eye, along with a sense of sadness for the fragmented human being. Undoubtedly, this media attention both creates new stereotypes and reinforces existing ones in the realm of the general public. Thus, the media impacts how the public interacts with those who are diagnosed with a disability such as an ASD. The theme of fragmentation is apparent within media representations on a variety of levels. In the most apparent sense, the autistic individual is often represented as being somehow “less than whole” with a fragmented mental health and personality. On a more obtuse level, autism is represented as something that will fragment a family and even the surrounding community. More recent studies on autistic families have reinforced these ideas, as they have shown high divorce rates and familial stress in families with one or more autistic child. Fragmentation themes originated during the time of Bettelheim and the psychogenic myth, when those experts on autism believed that autistic people were somehow broken or fragmented due to their condition (Sarrett, 2011). The theme of imprisonment of the autistic individual has also been commonly presented to the public. In this view, it is generally believed that a normal, neurotypical person is somehow trapped in an autistic shell of a body. Many of these depictions instill in viewers an urgent need to assist with releasing the individual from the confines of autism. This idea is intensified by an additional commonly-seen media trope of utter unawareness of self and others in the autistic person (Sarrett, 2011). Most recently, the media emphasis has been placed on the rise in rates of autism diagnoses and the idea of a possible autism “epidemic”. Again, it may be seen that the media attempts to highlight the most publicly enticing details or concepts behind ASDs (Sarrett, 2011). With this relatively prominent idea of an autism epidemic paired with a lack of education concerning the syndrome throughout the general public, it is understandable that the negative connotations and social stigmatizations associated with autism persist in today’s society.

Discussion

After understanding the history behind the scientific and social evolution of autism as an independent syndrome, one begins to see that there may be ways to foster a more tolerant and open understanding of those with autism in the United States today. A first step would include successful management of the syndrome. In order to ensure the successful treatment of an ASD, and to provide the best quality of life possible, a collaborative effort between all components of the health care team is essential. This collaborative effort should include clinicians, teachers, school workers, agents from outside support groups or foundations, the family, and the autistic individuals themselves (Quirantes, 2009). It is only through a strong and dynamic support system such as this that an autistic individual may truly strive in today's world. This open support and communication between all members also fosters a caring sentiment that promotes patience and adaptability in the team members. A willingness to adapt to the needs of each individual autistic child or adult is essential for those who wish to work with them, as the needs and personality of each autistic individual vary so significantly.

As research continues to move forward, it is equally important that a collaborative relationship is fostered between clinicians and researchers. Improvements must be made in each of these individual fields if significant future advances are to be made. Within the field of scientific research, specifically epidemiological studies, researchers should be pushed to identify social biases that could impact the population study samples, and to question how many children remain undiagnosed within each community. Researchers should also aim to study the syndrome across a range of communities and cultures, as comparative social bias and diagnoses range significantly (Lord, 2011). On a clinical level, education levels must be boosted in all health care providers concerning mental disabilities such as ASDs. Large organizations such as Autism Speaks and the Autism Society have worked to increase awareness for many years; however, the knowledge-base on ASDs in health care providers remains very low (Quirantes, 2009). While it is important for these health care providers to continue education on the general premises of autism, the application of this knowledge is arguably more important; therefore, it may also be concluded that methods of screening and treating autism should be improved as well. According to the American Academy of Pediatrics, it is important that children are screened for autism frequently and at a young age, so that children may begin to receive intervention services ideally before the age of 3 (Warren et al., 2011). In order to promote this early childhood screening, the American Academy of Pediatrics developed several new strategies for the identification of autistic children by pediatricians (Johnson & Myers, 2007). Within these strategies, it was suggested that once a child had been identified as at-risk for developing an ASD, a formal screening tool such as CHAT (Checklist for Autism in Toddlers), ITC (Infant-Toddler Checklist) or M-CHAT (Modified Checklist for Autism in Toddlers) should be employed. Without formal screening tools such as these, physicians are forced to rely solely on clinical impressions and have a much higher chance of misdiagnosis; however, it remains that only approximately 8% of pediatricians screen for ASDs on a regular basis (Quirantes, 2009). Another significant challenge for health care providers is diagnosing ASDs in children from ethnic minority groups, specifically those whose primary language is different from that of the physician. This difficulty is reflected in the current under-representation of minorities in mental health facilities and other support organizations. These low diagnostic rates in minorities are possibly due to actual lower rates of ASDs; however, studies have shown that this discrepancy is more likely due to the failure of physicians to generate a correct diagnosis. Forming an adequate clinical judgment on children from many ethnic minorities may prove difficult to many physicians, due to discrepancies in familial background or socio-economic status. Due to this mutual lack of understanding and communication, it has been seen that physicians are less likely to screen for ASDs in children from certain minority groups (Begeer et al., 2009). By increasing the rates of appropriate diagnosis through adequate usage of diagnostic tools, quality of care for autistic individuals may be significantly increased and more accurate rates of autism within communities determined (Quirantes, 2009). In this consideration, health care providers must take on the role of both advocate and support system.

While the importance of increased communication, more comprehensive research aims, and improved physician care should not be undersold, many consider the evolution of better social perception for autistic individuals the most important future progression. The social image of autism has improved dramatically since the creation of groups such as the US Autism and Asperger Association, National Autism Association, Autism Society, and Autism Speaks. These groups have worked to support ongoing scientific and sociological research, provide resources for health care providers and caregivers, and strive for an increase in overall quality of life for autistic individuals. Support services such as these have also played an important role in educating the general public on the intricacies of autism, and therefore in improving the general image of autism in the eye of society. Even more importantly, these groups have provided a safe outlet for the mixing of autistic individuals and their caregivers, which has prompted a significant increase in the numbers of autistic individuals speaking out to the public. The importance of this increase in autistic voices cannot be stressed enough, as they are truly the key to understanding the needs and emotions associated with ASDs. These public statements given by autistic individuals and their families work to counteract the current stigmatization and negative social perception that are so prominent in the United States today (Müller, Schuler, & Yates, 2008). Open narratives of life with autism are often particularly informative and communicative, as they present a comprehensive new perspective and challenge the reader to forgo pervious assumptions created by misunderstanding or media representations. This open communication stream flowing from many autistic individuals continues to be challenged by the silence of those that cannot or will not communicate, as this inconsistency brings questions about the generalizability of these autistic narratives; however, these new publications have driven the media to portray ASDs in a different light, as it presents a new face of autism to the general public (Sarrett, 2011). From the aforementioned statements, it may be suggested that an even further increase in autistic accounts is critical for the continued improvement of social perception of autism in the United States.

Conclusions

After considering the body of work that displays a history of misrepresentation and confusion regarding autism, one may easily understand the reasons behind the negative social perception which enshrouds the syndrome today; however, movement toward a more positive view is both tangible and promising. After decades of confusion concerning the origin of ASDs—be it biological, psychological or environmental—the American public has been concurrently intrigued and baffled by the condition; however, recent scientific breakthroughs paired with an increase in autistic voices has worked to combat this bafflement. While a significant amount of public relations work remains to be done, and many improvements are needed in all aspect of autistic care and treatment, it may be suggested that the social perception of autism has improved significantly since Kanner’s 1943 description and Bettelheim’s following theories. This research suggests that this boost in understanding and social awareness should continue to improve with greater public understanding of ASDs and continuing research to elucidate the foundations of the disorder.

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