

Why We Need a Shift in the Social and Medical Model of Our Approach to Autism

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Abstract

Autism is a neurotype experienced by over 75 million people worldwide. The DSM-5 describes autism as a developmental disorder with social communication deficits and a tendency to participate in ritualistic behaviors. In 2013, autism was renamed to autism spectrum disorder due to the heterogeneity in causes and outward behaviors of autistic individuals. The only empirical treatment for autism at the moment is the controversial applied behavioral analysis (ABA). In society, autism is often misunderstood and mischaracterized by stereotypes. These misunderstandings can lead to individuals on the spectrum feeling excluded from common activities or at a lack of general opportunities, causing feelings of rejection and loneliness. Additionally, current diagnostic materials and information sources on the topic are using harmful language to describe the traits of autistic individuals, thus further contributing to mental health issues like anxiety and depression. ABA has been criticized as trying to make autistic people more neurotypical, as opposed to accepting them for who they are and asking them for input into their treatment. Although it is important that autistic people self-advocate for their needs, paradigm shifts such as the double empathy problem and the social model of disability could change the way that treating and understanding autistic people is approached, and perhaps remove the underlying concept of normal altogether.

Introduction

Approximately one in 36 children are diagnosed with autism in the United States, with 75 million people impacted worldwide. This equates to 1% of the world's population being affected by autism, commonly known as autism spectrum disorder (ASD) (Elias, 2022). The National Institutes of Health (NIH) defines autism as a "neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave" (NIH). Common traits that exist in autistic people include difficulty maintaining eye contact, obsessive interests, and a need for sameness. These traits all exist on a spectrum, and some of these traits are not even present in certain autistic individuals. Autistic people are often significantly affected mentally and may feel excluded socially. Eighty-five percent of autistic adults are unemployed, with 70-80% of autistic people having mental health issues including anxiety and depression (BeyondAutism). More concerning, people with autistic traits are more likely to attempt suicide, (Cassidy et al, 683). These statistics indicate that this is a topic in need of addressing.

Many stereotypes exist for autistic people. In reality, autism has no unifying presentation. There is no one way that an autistic person is. Just like neurotypical people, autistic people are all different. There is a lot of heterogeneity when it comes to the ASD phenotype, as every autistic person has different outward traits and inner experiences. The autism spectrum ranges from low-support needs and the ability to function with relatively few difficulties in society to high-support needs and people who are nonverbal (Rudy). This heterogeneity is also reflected in the causes of the disorder itself and may be different for each autistic person. These differences in experiences and the fact that ASD is measured on a spectrum makes autism very hard to diagnose and treat. Overall, the quote by Dr. Stephen Shore, PhD, an autistic professor, "If you've met one person with autism, you've met one person with autism," holds true and

suggests that it is important to address an autistic person as an individual and not impose stereotypes on them.

Almost everybody in the U.S. has met someone who is autistic. Perhaps they were unrecognizable as autistic, because autism is commonly portrayed as people like the main character in *Rain Man*. *Rain Man* is a movie that was released in 1988 about the relationship of two brothers, neurotypical Charlie and autistic Raymond (nicknamed Rain Man). Rain Man is a 'socially awkward' routineer who engages in repetitive behaviors. This is the image that society had of autistic individuals in the 1980s. Since the release of this movie, the medical field has made significant findings and there has been great progress in many areas of society. It would therefore be expected that the autistic community has also become better understood and accepted, with more accurate representations of autistic individuals being shared with the public. Unfortunately, this is not the case. While there have been improvements to the public view of autism, autistic people are still in need of greater support in social situations, work and school environments, and sometimes even at home. While it is important that autistic people themselves are strong advocates for their needs, society should embrace autistic people for who they are and have the ability to support them. Currently there are very limited opportunities for autistic people to participate in society and everyday activities. So for what reason does most of society still see autistic people like Rain Man? Why has the narrative for autistic people not changed, despite the immense progress society has made since the 1980s? This review paper will aim to identify holes in the current structure of the way we think about ASD and modify the definition of autism as we know it.

Standard Diagnosis and Treatments

Diagnosis

The current criteria for diagnosing ASD in the U.S. is outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and was published by the American Psychiatric Association in 2013. The current diagnostic criteria require there to be deficits in social communication, as well as restricted and repetitive behaviors. The manual states that these traits must exist during the developmental period and need not to be associated with another intellectual disability. It is, however, important to note that ASD is often present with comorbidities, including but not limited to: epilepsy, sleep disorders, ADHD, anxiety, and depression (Bennett).

Social communication. Social communication is a key aspect in the diagnosis of ASD. The DSM-V lists some possible deficits that are often seen in autistic individuals. These include difficulty maintaining conversation, lack of understanding or use of nonverbal communication (such as gestures, eye contact or facial expressions), and struggling to develop or continue relationships.

Restricted/repetitive behaviors. Some behaviors that fall under this category include the repeating of motor movements (i.e., lining up cars/toys), difficulty with a change in normal routine/desire for sameness, special interests of a high intensity, and unique reactions to sensory input.



Severity. The severity of any of the above listed traits is also noted in the diagnostic process. The diagnostician can classify the severity of a trait on a scale from one to three. A classification of one requires the least support and three requires the most.

Early identification. ASD can be identified as early as 18 months old during developmental screenings. It is diagnosed through observation of developmental and behavioral history, which can be observed by the child's caretakers. A child's stage of development at certain ages is compared to that of typically developing children. If the child's development seems to be slower than average, an autism screening may be performed. An official diagnosis may not be given until the child is older and has had some more life experiences (CDC).

Difficulties diagnosing. The current assessment for diagnosing ASD is quite difficult, as the only way to diagnose the condition is via behavioral observations. Due to the heterogeneity and broadness of the spectrum of ASD mentioned above, many autistic people are undiagnosed as they do not fit all of the criteria, especially girls. When Hans Asperger discovered ASD in 1944, the disorder was initially only observed in boys ("The 'Extreme Male Brain': An Explanation for Autism?"). While this has changed since then, there is still a much higher diagnosis rate of autism in boys than girls. Perhaps this is because autistic girls simply have different behavioral patterns than boys. Many high functioning autistic girls have learned to make eye contact or participate in social situations. They are also better at controlling their behaviors in public, making it harder for clinicians to observe typical autistic behaviors in them (Arky). This is where a biomarker would significantly improve the diagnostic process. A biomarker is something associated with a certain condition that can be tested for using blood tests, genetic testing, brain scans, etc. (NIH). Researchers have been working for years to find a biomarker associated with ASD, but they have found that the heterogeneity of behaviors associated with ASD coincides with the heterogeneity of causes. While many genes have been identified in relation to ASD, only a small percentage of autistic people share the same genetic profiles (Al-Dewik et al. 1685). Certain differences in the structure of the brain have also been identified in autistic individuals, but brain scans alone have not been effective in diagnosing autism. This leads to a very subjective, behavior-based diagnostic process, thus creating an opportunity for missed diagnoses.

Importance of an early diagnosis. While the harm associated with a missed ASD diagnosis may not be recognizable by many, an early diagnosis is important to the development of autistic individuals. The knowledge that a child is autistic allows parents to seek support early and helps both parents and kids better understand certain behaviors. Growing up as an undiagnosed autistic child can have significant negative mental health implications due to feeling isolated and different from their peers. These effects are detrimental to the long-term health of autistic people (Mitchell et al. 10). Being aware of a diagnosis early also helps parents raise their autistic kids to communicate their needs (ie be a self advocate) - something important to the success of autistic individuals later in life. The child can also join communities with kids similar to them to combat loneliness and facilitate assistance in learning. Most importantly, an early diagnosis allows clinicians and therapists to be proactive in ensuring a successful development of communication. Given that autistic children often have speech delays as a part of overall developmental delays, a late diagnosis could mean missing the gap (before 3 years of age) during which communication can properly develop in the brain. Overall, an early diagnosis



can lead to the implementation of treatments early on in a child's life. The earlier a child receives treatment, the more impactful the treatment is long term ("Early Intervention for Autism").

Treatment

Currently, treatment options for ASD are very limited. While there are multiple approaches to improve the outcomes for autistic children, there are no treatments that will get rid of ASD or even remove the majority of its traits. Because of the heterogeneity of autism and the lack of knowledge about the causes associated with ASD, there is no way to approach autism pharmacologically (CDC). While coexisting conditions such as anxiety and depression can be addressed through medicinal interventions, the characteristics of autism itself are most often approached from a behavioral and developmental standpoint.

Behavioral. The most common behavioral intervention and treatment option for ASD is applied behavioral analysis (ABA) (CDC). There are many different models of ABA which have been developed throughout the years. A few examples include the Early Start Denver Model (ESDM) and Discrete Trial Training (DTT). Both of these models follow the general principles and goals of ABA, and it is recommended to start them as soon as a child receives a diagnosis (NIH). The earlier a child enters treatment, the more plastic their brain is. This allows for a more significant and permanent change in behavior. The goal of ABA is to change certain behaviors by analyzing the possible causes and effects of the behaviors (CDC). The outcome of this analysis will determine how clinicians can encourage desired behaviors and discourage undesired behaviors. Each child engages in a highly individualized treatment plan tailored towards the needs and desired outcomes of the individual and their families. Some commonly targeted outcomes of ABA are improved eye contact, communication skills, better attention and academics, and removal of self harm and other problematic behaviors ("Applied Behavior Analysis (ABA)"). Since this is an incredibly individualized process, ABA is most commonly practiced with an individual clinician for multiple hours a week. The amount of time spent in ABA depends on the child and the family's comfort level. It is, however, most common for ABA to take place for somewhere between 10 to 40 hours per week for 3-5 years ("How Long Does ABA Therapy Last? "). The setting also depends on the needs of the child and it often changes throughout a treatment plan. For some children, it is beneficial to hold sessions in a clinical setting where certain skills can be practiced repeatedly. Perhaps later in the process, they can move treatment sessions to a controlled or simulated natural environment. Simulated natural environments are often a good place for autistic children to practice their social or eye contact skills as it provides a smooth transition to applying the learned concepts to more natural environments (Bernier et al.).

Developmental. Since autism affects neurodevelopment, a lot of autistic people have difficulties with developmental skills like speech, coordination, and motor skills (National Autistic Society). For these ASD-associated difficulties, developmental interventions such as speech and occupational therapy are implemented. These kinds of therapies do not directly address autism, but they provide autistic people with the skills necessary for everyday life. The ability to communicate as humans is vital to human wellbeing, and unfortunately, the voices least heard in the autistic community are the ones who are non-communicative. If used early enough in the developmental stages, speech therapy or speech language pathologists can help those who would have otherwise been non-communicative to develop spoken language. Similarly, occupational therapy could help autistic people address any sensory issues, thus increasing

their desire to participate in various activities that would be otherwise difficult for individuals with sensory difficulties (“Benefits of Occupational Therapy for Autism”).

Alternative. As with most cases of neurodivergence, there are many possible paths that are successful in accomplishing the goals of autistic individuals and their families alike. That leads to a wide variety of alternative treatments available to try and help any difficult traits associated with ASD. In fact, most families do not stick with just one treatment option. Rather, it is the combination of various treatments that ultimately lead to a positive outcome (Bernier et al.). Some people have tried herbal medicine or special diets to help foster positive behavior. The use of a therapist using cognitive behavioral therapy (CBT) is also a common addition to a treatment plan. Additionally, having other adults in the autistic child's life be part of a treatment team is very helpful (Bernier et al.).

Treatment versus accommodation. When discussing treatment options, it is important to differentiate between treatment and accommodation. Treatment involves addressing the symptoms of ASD directly, through behavioral, developmental, or alternative interventions for improving a skill (Morin). The goal of a treatment is to change something. In the case of autism, the goal is to change various behaviors and the outcome for a child.

Accommodations, involve changes in various settings to help account for the various behaviors exhibited because of ASD (Morin). The goal is not to change any aspect of the person, but to find a way for them to thrive in an environment not originally suited for their needs. Examples of places where accommodations are beneficial for autistic people include school and work settings or public environments in which autism makes it hard to function fully.

The controversy surrounding ABA. ABA, the only empirically-based treatment for autism, is an intervention strategy aimed at improving socially relevant behaviors (Hendricks et al). This intervention has recently received a lot of support and pushback from various groups involved in the autistic community. The controversy around ABA stems from its origin in the 1960s. The first version of ABA was developed by Dr. Lovaas and was titled Discrete Trial Training. The methods used to promote positive behavioral outcomes included electric shocks and punishment, and these are unacceptable and no longer used today. However, many critics of ABA point to its original purpose and techniques as a reason why this kind of behavioral intervention should not still be the primary treatment option for autistic children. Additionally, autistic self-advocate Ari Ne’eman argues that ABA is simply teaching autistic children to act in a neurotypical manner and sending the signal that the natural behaviors autistic individuals engage in are unacceptable (“The Controversy around ABA”).

This feeling can be difficult for young children to understand and can lead to masking, which is the hiding of aspects of one’s true self, in order to be better accepted in social environments (National Autistic Society). Ne’eman also points out that the focus on eliminating ‘problematic behaviors’ does not account for the emotional value of engaging in these behaviors for the child. Dr. Catherine Lord, an autism researcher, recognizes the concerns of Ne’eman, but explains that ABA is meant to help a child reach their full potential in the world, not to change their thoughts and feelings (“The Controversy around ABA”). This debate about ABA has existed for a long time, and both sides have shared their opinions. The most optimal approach continues to be debated, with people from a variety of backgrounds and expertise levels contributing to the conversation.

Change in Approach

Applied Behavioral Analysis: Helpful or Harmful?

ABA is currently the only insurance-approved treatment for ASD in the United States, making it the most accessible to families with autistic children (Zauderer). Also, as the only science-backed approach to treating autism, ABA is the most trusted route of families looking to improve the outcome for their child. While there have been some positive proven outcomes of ABA in autistic children, some meta analyses show that the efficacy of ABA is questionable. According to one meta analysis performed by Yu and colleagues (2020), there are more aspects of ASD that ABA does not address than it does. The main positive outcome of ABA was in the realm of socialization, with improved social abilities and expressive language. However, verbal communication is not the only aspect of effective socialization, even though it is the most typical. This brings about the question of whether ABA is doing more harm than good for the majority of the autistic community.

The main skills addressed in ABA for autistic people are social abilities and repetitive behaviors. Autistic people are known to be ‘socially awkward’ and tend to have a hard time communicating with the neurotypical population. However, is it necessary for autistic people to learn to communicate with neurotypical people, or is it the other way around? It is not the job of autistic individuals to fit into a neurotypical society, because they are not neurotypical. The social differences of autistic people often include an inability to understand facial expressions or make eye contact (CDC). These are not traits that necessarily need ‘fixing’. The only reason certain therapies such as ABA aim to ‘fix’ these behaviors is because the neurotypical world considers them to be a problem. Autistic people engage in some of these behaviors for a reason. For example, stimming is the repetition of various behaviors and is a way for autistic people to let out stress or other emotions; it is soothing for them to repeatedly flap their arms or participate in other repetitive motions (Kotowicz). ABA should not aim to suppress these behaviors, since they are providing comfort to the autistic individual. Another focus of ABA in autistic people is their difficulty with making eye contact. Autistic people often feel that they have to choose between making eye contact and participating actively in a conversation (Kotowicz). Making eye contact is an active task for many people with autism, and it requires energy to do so. Therefore, society needs to become more accepting of all types of people and behaviors instead of forcing societal norms on the neurodivergent community. By suppressing stimming behaviors and expecting eye contact to be made, autistic people get the message that their natural way of being is unacceptable and needs to be changed. This can lead to negative self esteem and mental health issues like anxiety and depression (Cox).

When it comes to ABA’s desire to improve social abilities, there are some mixed opinions, and no one answer is right for everyone. Many autistic people are non-verbal, and ABA is proven to increase the likelihood of speech developing in non-verbal autistic children (Bernier et al.). This may make ABA appealing to families with nonverbal autistic children, but it is important to note the presence of other options. For children who appear to be non-communicative at an early age, an alternative to teaching children to speak could be introducing multimodal communication. While verbal communication is preferred by society, speaking is not the only way to communicate. Since most autistic children are not motivated by social factors from a young age, using pictures or symbols to communicate (i.e., visual communication) may be easier for them to understand (Rudy). Their ability to speak is less important than their ability to

communicate, and if they miss the crucial window of communication developing in the brain, they could miss their chance at having significant control over their lives (“Speech and Language Developmental Milestones”). For that reason, treatments like ABA should be less focused on teaching autistic children to speak, and place more emphasis on teaching communication in general, no matter whether that is verbal or visual communication.

Many autistic people argue that ABA is trying to make autistic people more neurotypical (“The Controversy around ABA”). While this is not the direct purpose of the therapy, the associated goals often translate to creating a more neurotypical person. It is reasonable to say that behaviors causing injury to oneself, such as banging one’s head against a wall or hair pulling, should be addressed as quickly as possible. However, these behaviors serve a purpose to an autistic person, and cannot simply be removed. The autistic person is receiving some sort of sensory pleasure through the self-injuring activity, so it is important to first look at the sensory purpose being served by the behavior. Then, it could be helpful to see when these kinds of behaviors are occurring. Perhaps when coloring, an autistic child would take pleasure in chewing on colored paper. This obviously poses health concerns and needs to be addressed. In her podcast on sensory issues and autism, Dr. Mary Barbera recommended checking on the mineral levels of things like lead, zinc and copper in the child’s blood because they are often the cause for behaviors like this. Otherwise, if a child has issues with say, wearing a jacket in the wintertime, and expresses these sensory issues through self injurious behavior, the child’s parents and treatment team can try to desensitize the activity. This happens by slowly practicing certain aspects of a situation until the child becomes more comfortable with it (Barbera).

For the other behaviors addressed through ABA, the extent of the treatment should be up to the autistic person. If they truly desire to fit into a more neurotypical society, then certain social aspects can be practiced. This must be done cautiously, though, so as not to cause the autistic person to mask their true selves. Masking is often the reason that autistic people go undiagnosed, but it can cause more problems than that. When autistic people mask their true selves in order to fit in better socially, even if the masked version of them is accepted by their peers, an innate fear of rejection can arise (Mitchell et al. 10). They feel that their friends do not accept their true, authentic, autistic selves, because the autistic person has never allowed them to see that side of them. This can lead to a cycle of feeling lonely and rejected, which causes mental health difficulties (Mitchell et al. 10). Therefore, it is important to leave the majority of the things being treated up to the autistic individual, with communication and self-injurious behaviors being the only exceptions. The early introduction of multimodal communication and the replacement of self-injurious behaviors with healthy behaviors which provide the same sensory experience for the autistic person could be possible remedies to these difficulties. Overall, society needs to become more accepting of all types of people, so that autistic people do not feel the need to change themselves in order to fit in. Most importantly, society does not have the right to change autistic people and their behaviors for the benefit and comfort of others. Autistic people are humans too and they have the right to choose their own path.

The Harmful Effects of Language used in the DSM

Currently, to diagnose ASD in the United States, clinicians turn to the guidelines outlined in the DSM-V, which was published by the American Psychiatric Association in 2013. The guide explains the diagnosis: “To meet diagnostic criteria for ASD according to DSM-V, a child must have persistent deficits in each of three areas of social communication and interaction plus at

least two of four types of restricted, repetitive behaviors” (American Psychiatric Association). The word “deficits” implies that something is inherently wrong with the natural state of being of an autistic person. It suggests that autistic people are faulty, and are missing factors that would make them ‘normal.’ This vocabulary raises questions. What defines normal? And why is a diagnostic criteria causing clinicians to make a diagnosis based on how ‘normal’ someone is?

Late-diagnosed autistic adult Melissa Tacia poses these questions in her podcast “Oh, That’s Just My Autism” during an episode related to the DSM-V (Tacia). She emphasizes that the criteria for diagnosing ASD is too vague and points to phrases such as “interests that are abnormal in intensity or focus” as evidence (American Psychiatric Association). She believes that the criteria do not provide diagnosticians with something to compare the behavior of a possibly autistic person against. Tacia also sheds light on the fact that words such as “deficit” can negatively impact the mental health of autistic people (Dinishak), and the vagueness in criteria leads to a lot of underdiagnosing in the autistic community.

Tacia mentioned in her podcast, that a large group of the autistic community remains undiagnosed with the current DSM-V guidelines in place. She argues that based on the current diagnostic criteria, clinicians are looking only for severe manifestations of behaviors listed. Therefore, those who are engaging in similar behaviors on a less obvious level (like many autistic girls) can fly under the radar. Thus, Tacia believes that a main contributor to the underdiagnoses is the type of language used in the DSM (Tacia).

The verbiage “persistent deficits” indicates a high level of severity, and “abnormal” is very vague. Another important fault of the verbiage used in the DSM, is the use of the word “symptoms” to refer to traits often present in autistic individuals. The NIH now recommends using the words traits or characteristics, instead of symptoms when referring to ASD (NIH). As mentioned before, the DSM was last published in 2013 by the APA. Since the adoption of the fifth edition of the DSM, there have been a lot of new findings for the autistic community, and autistic advocates have spoken out about various issues related to the treatment of autistic people. For example, more information has been gathered on the prevalence of autism in girls, as female children have been historically underdiagnosed when it comes to autism (“Autism in Girls and Women”). It is therefore vital that more specific descriptions and examples of ASD’s presence in all genders is provided. More and more women are finding out they are autistic as adults, and wish that they had had that knowledge as kids. In response to this childhood underdiagnosis, there needs to be more variety in the diagnostic guidelines that captures the true heterogeneity that exists in the autistic community.

In modern society, neurotypical kids are often told: “it is okay to be different, there is no normal! What does normal mean anyway? If people were not different, the world would be boring!” It is good that society is shifting away from the idea of normal and accepting lots of different people, but that narrative shifts when we start talking about the neurodivergent community. As soon as someone is different enough to be neurodivergent, there suddenly *is* a normal to compare them against. For autistic people, interests are “*abnormal* in intensity and focus”, and differences in communicating translate to “*deficits* in social communication” (American Psychiatric Association). This underlying concept of normal may have primarily disappeared for the neurotypical population but is still very much existent for the neurodivergent groups. This is supported by documents like the DSM, which still uses criteria based on the ‘normalness’ of behaviors to diagnose autistic people. Using language like “deficits” and

“abnormal” in something as important to the autistic community as the diagnostic criteria is extremely harmful. It sends the message to an autistic person that they are not good enough and that their brains are lacking what is needed to fit in or be ‘normal’. This will inevitably lead to masking and a negative self view, which has a significant negative impact on mental health. The neurotypical world has begun accepting different kinds of people, shifting away from the use of the term ‘normal’. Now we need to accept the neurodivergent community in the same way, and not compare them to a made-up concept.

Autistic People are not the Issue: the Importance of the Double Empathy Problem

Autistic people are constantly told that they are the problem. It is almost like their brain is inconvenient to the rest of society. They are told that *they* are the ones with social difficulties and deficits in communication. However, what if this was not actually the case? Autistic researcher Jac den Houting claims that their autism diagnosis was the best thing that had ever happened to them, and upon researching the diagnosis was surprised to learn that what had been so important and positive for them (their autism), was perceived as something negative in the medical model (Den Houting). Perhaps the neurotypical community is equally responsible for the communication ‘challenges’ that autistic people face. Maybe there is an invisible barrier between the two communication methods, and only through breaking the barrier is it possible to have clear communication across neurotypes. These questions are all addressed through a paradigm shift called the double empathy problem. The double empathy problem, a term coined by autistic autism researcher Damian Milton in 2012, suggests that it is neither autistic people nor neurotypical people that have difficulties communicating. Instead, it is the mismatch between the neurotypes that makes communicating with autistic people seem challenging (Milton, 883-887). This shifts the paradigm from the deficit model (i.e., assuming that autistic people have deficiencies) to a model emphasizing mutual communication. A few experiments have been done to test this theory using both autistic and non-autistic people.

The telephone experiment. A study conducted by Crompton and colleagues tested the idea of the double empathy problem in a game of telephone (1707). In total, nine groups of eight people were arranged. Three of the groups contained only autistic people. Three groups were made up of only non-autistic people. The last three groups were made up of a mix between autistic and non-autistic people, alternating (**Fig. 1**). The researchers shared a story with one person in each group and asked them to impart the story on another member of the group until everybody in the group had heard the story. After each game of telephone, it was found that the groups made up of people with the same neurotype (i.e., only autistic and only non-autistic people) shared information equally as well. However the groups consisting of people with mixed neurotypes had significantly lower rates of information sharing. Additionally, members of the mixed group rated people of the opposite neurotype lower on measures of rapport than members of the same neurotype. This finding would support the hypothesis of the double empathy problem, as communication was clearly more difficult for the mixed neurotype groups than it was for the same neurotype groups. This would provide reason to believe that autistic people better understand other autistic people and the same for non-autistic people.

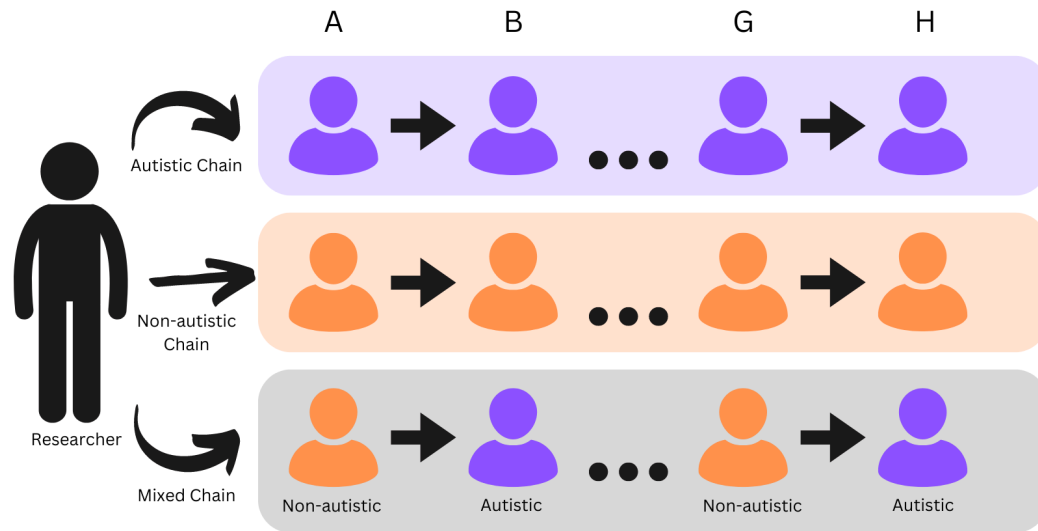


Figure 1. Depiction of diffusion chain method. Visual representation of diffusion chain experiment conducted by a researcher where only autistic people, only non-autistic people, and a mix of both autistic and non-autistic people shared a story in a game of telephone. Adapted from Crompton et al. 1706.

Interpretation of autistic people. A few studies by various researchers were conducted to test the perception of autistic people by neurotypical counterparts. In a study by Sasson and colleagues, a video was taken of a 60-second practice audition performed by autistic and non-autistic people for a reality/game show (2). The audition was judged by non-autistic viewers. The clips were shown to viewers with the following modifications: (1) audio-only, (2) visual-only, (3) audio-visual, (4) static image, and (5) transcript of speech content. The viewers were not informed that some auditioners were autistic, but when asked to rate the favorability of the auditioners, non-autistic people were rated more highly than autistic people. However, when asked to rate the favorability of the transcripts of both groups, no one group came out on top. This suggests that it is the outward behaviors of autistic people that causes them to be discriminated against by their neurotypical peers upon first impression, not the content of their speech (Sasson et al. 7). This finding would be in line with the ideas of the double empathy problem. As a species, humans prefer people with similar traits and behaviors to their own (Seidman).

Nevertheless, there are studies that could contradict the hypothesis of the double empathy problem. Although studies like the one conducted by Crompton and colleagues would provide a basis to believe that autistic people favor other autistic people, a study by Grossman and colleagues wanted to see if the autistic people would innately favor other autistic people, without the explicit disclosure of a diagnosis (846). In the study, teenagers with and without autism were asked to watch short video clips of autistic and non-autistic people. It was found that both groups spent less time looking at the videos of autistic people. Furthermore, the videos of autistic people were judged more negatively than non-autistic people's videos by both autistic and non-autistic people. Given the ideas of the double empathy problem, it would have been

assumed that autistic people would judge fellow autistic people's videos more highly than the non-autistic people. However, the double empathy problem proposes that the difficulties in *communication* are caused by a mismatch of neurotypes, whereas this study focused merely on initial impressions. Moreover, an argument could be made to describe the reasons why this first impression does not follow what would be expected considering the double empathy problem. Many autistic people tend to mask their true selves in social situations, becoming more 'neurotypical' to better assimilate into the neurotypical culture of their surroundings (National Autistic Society). This would propose a positive association between the behaviors of neurotypical people, and the behaviors autistic individuals wish to emulate within themselves. Although masking uses a lot of energy for the autistic person, this process often happens innately. For this reason, it would make sense that autistic people prefer the social interaction capabilities of neurotypical people, because society has made those behaviors seem like they are the most desirable and acceptable. If society normalized the idea that there is no normal, it would be intriguing to redo the study and see if the findings differ.

The harm of masking and its significance to the double empathy problem. As mentioned previously, the process of masking is extremely detrimental to the mental health of autistic people (Mitchell et al. 10). Not only does masking occur because autistic people feel as though they are not accepted the way they are, but it can lead to loneliness despite the apparent presence of a social community (Mitchell et al. 10). The feeling of loneliness is unfortunately a very common sensation experienced by the autistic community. As a young child, especially if ASD has gone unnoticed or undiagnosed, social interactions can be quite difficult and the differences in behavior of autistic people lead to a lack of understanding by their peers (Neff). Given that humans have an innate desire to be a part of a community (Cohen), autistic people mask their true behaviors to be included in social groups. This masking occurs in part as a result of the double empathy problem and the mismatch of communication styles between autistic and non-autistic groups. Despite the apparent success of this strategy, the feeling of loneliness can persist. This may be due to the fact that through masking, autistic people never show their true selves, which means who they really are is never accepted by their peers. Autistic people are of the opinion, and evidence from studies like Sasson and colleagues agrees with this, that unveiling their real personalities will lead to their exclusion from society (7). This further exacerbates the need for change in society. Without more understanding of what being autistic means, more places where autistic people can feel safe, and a communication type that both the autistic and non-autistic communities can understand, this feeling of loneliness will continue, and can lead to severe manifestations of anxiety and depression.

Social model of disability. One other important concept associated with autism and the double empathy problem is something called the social model of disability. This model discusses the difference between a disability being something caused by oneself versus a disability being caused by the environment. This model opposes the traditional medical model approach to a disability, which posits that a disability is within the individual and its associated challenges are not 'normal', thus needing to be cured or fixed. Instead, the social model of disability places the blame for a person having difficulties in their life on the environment (Buder and Perry). Consider the following example: a person in a wheelchair needs to use an elevator to go up to a higher floor, but the building does not have an elevator. The medical model would consider this a problem within the person in the wheelchair, as they are the one who cannot walk. On the other hand, the social model of disability would consider this a problem with the



environment. The person in the wheelchair is unable to reach their goals because they are disabled by their environment, not the other way around. This concept can also be applied to the double empathy problem. Looking at autism from the perspective of the social model of disability allows us to look through a different lens. The more we take the blame off of autistic individuals for the difficulties they face, the more society will come to learn about what being autistic really means and the importance of trying to understand a variety of neurotypes. It would alleviate a significant amount of mental health issues for autistic people, if we start looking to help them by changing their environment, not forcing change upon *them*.

Conclusion

It is time to flip the narrative. Autistic people have advocated for themselves, but their voices are subdued by the allegedly more knowledgeable voices of the population educated in the medical model, telling autistic people and the general public what treatments they need to become 'more normal' and how they should behave to be accepted socially. If there was no preexisting idea of 'normal', autistic people would not be ostracized for their 'abnormal' tendencies. If autistic people were given more input into *their* treatment and could become self-advocates, perhaps they would be more pleased by the outcome and have less mental health challenges. And maybe if society accepted autistic people the way they were, there would be no need for treatment, just changes to their environment. As the social model of disability explains, the environment disables the person, not the other way around. If this is the case, then it is necessary to change the environment and make it a place more open to accepting autistic individuals. While a portion of changing the environment relies on the ability of the autistic person to self-advocate by stating their accommodation needs, the majority of the responsibility to change the environment is in the hands of the non-autistic community. If society does not fully understand autistic people and still considers them all *Rain Man*, the autistic community will hardly get anywhere when self-advocating. For this reason, autistic people need more opportunities to share their real experiences and thereby gain sympathy from the non-autistic population. It is the latter population's sympathy that will lead to environment shifts large enough to positively impact the success rate of autistic people in society.

It is time we shift the paradigm and redefine autism. Autism is not something negative or abnormal as explained by the deficit model, but instead is something beautiful and necessary to the diversity of the planet. If each person changes just the way *they* think about autism and neurodivergence in general, it will make an immense difference. More autistic people would be given multimodal communication opportunities, because being communicative is more important than being able to talk. ABA would not be the first step in helping an autistic person. Instead, changes to their environment could make an autistic individual feel seen, heard, and confident in their ability to succeed. Autism would not need to be diagnosed using criteria based on how 'normal' someone is. A new understanding of autism could make different criteria for different genders and age groups, using positive language that does not impact the self-esteem of the autistic population. At some point, maybe there would not even be a need for a diagnosis, because people would just be accepted as they are without an obligation to justify accommodations. Most importantly, by recognizing that many of the difficulties autistic people face are caused by the environment, autistic people would struggle less mentally, and learn that they do not need to mask themselves to be accepted. Society needs to accept them for who they are.



Neurodivergence is a social construct, and one that we no longer have to abide by. There is no neurotypical or neurodivergent, because if there is no 'typical,' then there is no 'divergent.' By letting autistic people be themselves, without labels, and supporting them in any way possible, we are validating their humanity and sending the message that everyone, no matter who they are or how their brain works, is welcomed as an equal in society.



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