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ijhighschoolresearch.org
REVIEW ARTICLE

# The Diversity within Neurodiversity: Recommendations for a New Approach to ASD Treatment Priorities

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ABSTRACT: This paper discusses the complicated and intertwined factors and controversies surrounding neurodiversity, with a particular focus on Autism Spectrum Disorder (ASD). Not only is the nature of neurodiversity multifaceted and sometimes hard to characterize, but there are also multiple factors and controversies affecting treatment planning. Due to the complex nature of ASD, it is proposed that the standard practice of basing treatment priorities heavily on parents' major concerns should be reconsidered and that a more systematic and objective education program and categorization approach should be developed in future research.

KEYWORDS: Behavioral and Social Sciences; Clinical and Developmental Psychology; Neurodiversity; Autism Spectrum Disorder (ASD); ASD Treatment Priorities.

## Introduction

Neurodiversity has become a hot topic in recent years and has stirred up a great number of controversies. The term "neurodiversity" was first introduced by Judy Singer in 1998 as part of the autism rights movement.[1] It implies that neurological differences and the resulting behavior should be treated and respected as forms of natural human variation.[2] In other words, although some conditions might appear to be deficits and "inconvenient" to have because they make it harder for individuals to fit into the norms of society, these conditions should not be treated as "abnormalities" or illnesses that need to be cured. Researchers have further found various strengths, or natural talents, associated with having these neurological conditions. Specifically for individuals with Autism Spectrum Disorder (ASD), which contributes to a large portion of the neurodiverse population and seems to attract the most attention in research, talents in music, math, memory, and spatial skills are among the many strengths that have been commonly found.[3] However, many ASD individuals are unable to utilize their special strengths due to a variety of reasons, and it is certainly a loss not only to them but also to our society as a whole. As a result, this paper not only explains the less-apparent sides of ASD, such as some of the common strengths that tend to come with it and controversial topics surrounding it but also proposes the development of education and communication tools to help patients and families make well-informed decisions together with their clinicians.

## Discussion

### *I. Complicated Nature of "Neurodiversity":*

Neorodiversity is a very complicated topic from many aspects.

#### *A. A Diversity of Models:*

There are multiple models that view the nature of neurodiverse conditions from very different perspectives. The most prominent framework for understanding autism, historically, is a medical model where ASD is treated as a disability. While the medical model takes a more traditional view to see ASD as deficits to be treated and corrected, a strength-based model focuses on developing such individuals' areas of strength. It considers a more comprehensive panel of criteria, such as talent in music or even other daily tasks the individuals are better at, that could help them excel and have a sense of accomplishment. In turn, these strengths can be used to motivate them to work harder on other necessary skills and aspects.[4] In addition, there is a social model of disability that sees the challenges of these individuals as the responsibility of society as a whole. In other words, society fails to see these variations in brain functions as normal in humans and does not provide enough flexibility and space for these variations.[5] Whether it is the medical, social, or strength-based model, they are each with a very different perspective, and the treatment decisions based on the different models will likely be very different.

#### *B. Identity-First vs Person-First Language:*

Besides the different models mentioned above, there are also controversies in terms of how to refer to these individuals. While self-advocates usually prefer being addressed in identity-first language ("autistic individual"), the person-first ways, such as "individuals with autism," are usually preferred by advocates for them such as parents.[2] One of the reasons that many self-advocates prefer identity-first language is because they feel this identity should be something to be celebrated. One analogy that is often heard among those in favor of identity-first language is, as a proud American, people would say that they are American citizens, instead of people with American citizenship, and therefore, instead of individuals with autism, they would like to identify themselves as autistic individuals. For the purpose of this paper, person-first and identity-first language will be used alternatively to represent views from both groups.

#### *C. "High" vs "Low" Functioning Autism:*

Furthermore, there is also controversy regarding the labels of "high functioning" and "low functioning" autism. Usually, so-called high functioning refers to people who are not cognitively compromised and have a normal Intelligence Quotient



DOI: 10.36838/v4i6.8

(IQ) range of 70 or above.[2] This group usually exhibits behavior that is closer to the "normal," or the neurotypical, majority. The other group, the low-functioning ones, has an IQ range of 70 or lower. However, questions arise about whether IQ testing is even an appropriate measure to determine intelligence levels for ASD individuals. For example, for non-verbal, occasionally also referred to as non-speaking to emphasize impairment over being non-functional, individuals on the spectrum, sometimes even the verbal ones, such testing designed for the neurotypical majority could end up being a very biased way of measuring their cognitive ability.[6] In other words, non-verbal ASD individuals can score very low on IQ testing due to their inability to communicate, not actually due to their low intelligence levels. As a result, giving the high and low functioning labels is not only controversial but could be a very poor indicator of intelligence in the autistic population

***D. Asperger's Syndrome in ASD Diagnosis:***

Moreover, Asperger's Syndrome, which used to be a separate diagnosis from ASD, has now been part of the spectrum since the release of the DSM-5 in 2013.[2] Individuals with Asperger's, although experiencing various challenges due to the neurological differences, are usually said to be "high-functioning," and sometimes even "twice-exceptional" with IQ measured over the levels 120 or even much higher. From the perspective of the medical model, although Asperger's' patients experience the same social and communication deficits, some argue that including it in ASD misrepresents the condition because the level of "deficits" or "disability" associated with Asperger's is usually much lower than others in the spectrum.[2] Some go further saying such misrepresentation jeopardizes other ASD patients' chance of getting disability benefits or accommodations because it gives the general public the wrong image that all individuals on the spectrum are savants since some individuals with Asperger's are especially talented in certain ways, such as memory and math.[3] An example that is often referred to is Barry Levinston's 1988 film, Rain Man, and for the general public who are less experienced with this group of the population, this might become the only source of information and impression they have for people on the spectrum. Whether or not Asperger's should be included in the spectrum diagnosis is beyond the scope of this paper, but this controversy further highlights the complex nature of ASD.

***E. Altered Perceptions Over Time***:

It is also interesting to note that while previous research has estimated that 70-80% of ASD individuals were cognitively impaired with IQ levels below 70,[7,8] more recent 2014 CDC studies indicate only 31% are estimated to have such impairments.[9] One reason for the discrepancy could be due to the inclusion of Asperger's in the ASD diagnosis, which increases the number of normal to high IQ patients. Another reason may be that with more research and knowledge in the field, many of the originally "less obvious" cases with less noticeable symptoms are now being correctly diagnosed. Now that individuals with fewer cognitive impairments are being correctly diagnosed with ASD, the prevalence of impairment in the population has reduced. This trend certainly helps reduce the overall stigmatization of ASD, where now a significantly lower portion of diagnosed patients are being labeled as cognitively impaired. On the other hand, it again brings up concerns about its impacts on patients' chance of obtaining disability benefits, because ASD could then be perceived by the general public as just a relatively minor variation in terms of communication and social skills.

***II. Factors and Considerations in Treatment Planning:***

As can be seen, there are many controversies around the ASD condition. However, even more arise regarding the best practices of assessment and intervention for these patients.

***A. Intervention Needs Dependent on the Nature of the Behavior***:

First, it is worthwhile noticing that even strength-based and social-model advocates would agree that certain ASD behaviors undoubtedly need interventions.[10] The most obvious cases are individuals with self-inflicted injuries or physical aggression towards others. For the cognitively affected and even some of those with more typical cognitive abilities, it is usually the consensus to emphasize the importance for them to develop the necessary life skills to help themselves with self-care and to achieve as close to independence as possible.[8,11] However, in terms of certain social behavior, it is now divided whether certain behavior previously considered "socially inappropriate" should now be taken as acceptable through more awareness in the general public.[12] The most obvious example is stimming, which often involves repetitive physical movements or sounds, for ASD individuals. Individuals on the spectrum stim for purposes such as releasing sensory overload so they can calm themselves down and perform better.[13] While such behavior does not harm anyone, it is often perceived as simply weird or "inappropriate" because it is not done by others. Then questions arise as to whether such behavior needs to be corrected for autistic individuals to be more easily accepted in society.[10,13] Because correcting such harmless behavior is counter-productive to sensory overload, researchers have found it unnecessary and even harmful to try to correct it.[13]

***B. Extent of Being Beneficial and Practical in Inclusion:***

Nevertheless, whether it is practical not to treat some relatively non-harmful behaviors is sometimes not a simple question. ASD itself is complicated, not to mention that it also often comes with other conditions such as ADHD, OCD, and Tourette's.[14,15] Different conditions indeed bring different possible strengths to the individual, and the goal of neurodiversity advocacy is often for society to have enough awareness to accommodate their various special needs so that these individuals will get a chance to develop and make use of their strengths.[12] However, today's society is not as accommodating as it ideally should be, and therefore, whether ASD individuals should "fix" some of their neurodiverse behavior so that they can get a better chance to fit in and use their strengths in this society has become a question of debate.

For example, while it would be ideal for the individual to get a customized 1-on-1 education to develop those strengths, it is often not the most budget-friendly. Including students with


DOI: 10.36838/v4i6.8

special needs in regular classrooms, or called "inclusive classrooms," is the more common approach to developing higher-level skills because these skills, especially academic ones, are taught in those classrooms. While teachers in inclusive classrooms can be trained to use tools and strategies such as assistive technology, seating arrangements, buddy systems, and modified lesson plans, to make the class more inclusive, children with autism might still have a hard time paying attention and learning in such a classroom setting, and some autistic behavior, such as difficulties taking turns and tendencies to speak loudly or off-topic, might make it impractical for them to be included in such a classroom as they may "interfere with instruction or attempts at inclusion."[16] Also, even if under a preferred case where a teacher is trained to handle students with various conditions in an inclusive environment, a limited budget might not always allow the class size to be small enough for such a teacher to implement all the necessary accommodations while taking care of a large classroom of students. Sometimes it works when the budget allows a trained aide to be with the special-education student in the regular classroom. However, this may or may not be enough because such a student may require a structured approach with "explicit teaching" and an "experienced, interdisciplinary team of providers."[14]

Therefore, it is often not practical to expect that students with special needs can completely "be themselves" while the teacher can also keep a sizable classroom of students in a proper environment for learning without frequent disruptions. Under such circumstances, a dilemma arises as to whether students with such conditions should learn to fit into the norm so that they can be "included" in a regular/inclusive classroom setting to learn more and to develop their strengths, or if they should be allowed to be themselves and be separated in special-education classrooms that often have lower academic expectations.

***C. The Two Sides of Masking Behavior:***

Another relevant issue is masking, which is when ASD individuals copy the behavior of neurotypicals to make themselves appear to be more "normal." It is not unusual for ASD individuals to learn to mask, or camouflage, their conditions, either knowingly or unknowingly to themselves.[17] Some might be aware of their atypical thoughts and behavior and intentionally learn to hide them by pretending to behave like the neurotypical. Others naturally learn to copy others' behaviors to act to the norm, even though such actions might not make sense to themselves or sometimes are even so unnatural to the point that it becomes psychologically painful in the long term.[17] Masking behavior does make autistic individuals appear to be more normal and often helps them fit in socially. However, these experiences can be "exhausting, isolating, damaging for their mental and physical health, identity, and acceptance of self, creating unreal perceptions and expectations of their abilities for others, and in some cases led to a delay in formal diagnosis or a mental health crisis."[17]

Although due to the long-term stress and the various negative psychological impacts of "pretending," masking is not recommended by many professionals, the group of ASD individuals who learn to mask tend to possess higher cognitive ability and feel they have more involvement or "access" to the social world.[17] Without such higher cognitive ability, it would not have been possible for them to figure out the difference and to copy the atypical behavior and responses in the first place. Also, they tend to be the group who will have a higher chance to live independently, feel a sense of achievement, and have relatively "normal" or even "successful" lives, whether it is due to their higher cognitive ability or as a result of their success from looking "normal" to fit in.[17] Ideally, society should learn to accept a diverse range of behavior due to neurological differences, but in an imperfect world, it is sometimes still a dilemma whether they should be encouraged to mask their conditions at the cost of long-term mental well-being.

***D. Issues with Diagnosing "Twice Exceptionality":***

There is also a group of especially high IQ ASD individuals who are often called "twice-exceptional," people who are special both in terms of "deficits" and talents. Depending on how visible the autistic traits are, they tend to go undiagnosed for ASD and unidentified for being gifted.[18,19] First, their exceptionally high IQ, typically greater than 130, often makes their challenges less visible.[18] One might think that this is not a big deal because the person acts just like the rest of the ones around, but in reality, it is often frustrating. For example, such an individual might constantly feel that they are talented or very capable of outsmarting their peers but get frustrated at the fact that they are never able to demonstrate that in reality because their talents are "crippled" or limited by their ASD challenges such as social or communication skills that make those advantages impossible to be seen or identified. On the other hand, not being identified for their ASD challenges because of their especially high cognitive abilities also places such individuals in constant confusion as to why the world around them seems to operate in ways that do not make sense to them. As mentioned above, although individuals with ASD might not understand certain things that neurotypical individuals understand and do naturally, some of them learn to mimic the behavior of neurotypicals well enough that they end up undiagnosed. There are many such cases when ASD individuals are finally diagnosed with ASD later in life, they experience tremendous relief because they can finally find out why they have been feeling that way all their lives.[1] As a result, while such individuals might appear to function adequately alongside their neurotypical peers, it is important that both the ASD and the giftedness are identified. Moreover, as a note, currently twice exceptionality is based on higher IQs, but there are also ASD individuals who either possess natural strengths in areas not measurable by IQs or are limited by their symptoms such as their verbal abilities that make them unable to demonstrate such high IQ levels, further complicating the assessment of twice exceptionality and their subsequent treatment and development plans.[6]

***E. Dilemmas in Allocating Resources:***

Although many ASD individuals possess natural talents in certain areas, dividing resources such as time and budget between working on ASD symptoms and developing the strengths is often a real challenge. For example, it might be

very important for speech therapy to take place regularly for a non-verbal ASD individual, but it will also be a waste if such an individual's time is mostly devoted to therapy and not to his exceptional music or math talent that could potentially bring much higher self-esteem and even a successful career. On the other hand, if time and resources are devoted to developing music or math talent, the individual might lose the opportunity to spend enough time to be able to communicate better to live a relatively independent life.

***F. Facing Multiple Conditions:***

Having multiple conditions, whether directly related to ASD in nature or other unrelated physical or psychological conditions, also impacts treatment planning. Besides having multiple neurological conditions and/or being cognitively compromised, other physical or psychological challenges are also commonly found among ASD individuals. As mentioned in section II.B, some ASD individuals have other neurological conditions such as ADHD and Tourette's Syndrome and/or medical challenges such as other chromosome abnormalities.[14] Studies have also shown that they also tend to develop other psychological disorders such as depression and anxiety due to the constant stress, either from having to mask their behavior to fit in or from never being able to feel accepted or having a sense of belonging in community.[20, 21] In addition, these individuals also tend to have more medical conditions related to gastrointestinal issues, sleep disorders, and seizures.[22] These additional conditions certainly make intervention decisions a more complicated process.

***G. Environmental Factors:***

Environmental factors such as resources available to the individual can play an important role in interventions as well.[23] Family support, financial stability, state or public education funding, as well as available specialized physicians nearby also contribute to what and how interventions will take place. For immigrant families, finding specialists and therapists who can speak their language and communicate in a more culturally sensitive context will be important. Family status, such as domestic conflicts, as well as support from extended families and grandparents also play a factor in determining the frequency and the extent of the intervention. Moreover, if a parent or a sibling also has special needs, or if there are new additions to a family, it will also affect how much focus could be placed on the particular ASD individual. Furthermore, the particular county's funding for intervention programs, as well as the school district's commitment to special education, all play vital roles in interventions. As a note, since COVID-19, many services are available online through telehealth platforms such as Zoom, making many previously inaccessible services and therapists available to patients not in the same geographic area.[24] Although it is unclear whether the use of telehealth platforms will continue to be a trend after the pandemic, it has certainly opened the doors for seeking professional services that were physically out of reach.

***H. Changed Priorities Over Time:***

Finally, it is critical to assess treatment progress regularly and use that as a factor in future treatment planning. Sometimes progress such as the ability to retain previously learned skills should be used to determine which types of interventions are appropriate. Reaching a certain goal might not mean a shift of focus should be implemented. The same treatment plan and goal could still be considered of higher priority especially if it involves great effort and time to achieve the level of success. An example could be academic performance in a certain subject. Reaching a certain grade level in a particular subject might not mean the effort should stop there. On the contrary, consistent effort should be made to ensure success in the long run, and the positive experience will likely foster higher self-esteem and motivate the individual to make more effort either in the same or other areas. As another example, certain unwanted behavior such as aggression toward others might be regarded as an important milestone in intervention, but even if it has been stopped earlier in the treatment, such concepts should continue to be reinforced during the intervention as prevention.

As can be seen, there are a variety of factors unique to each patient that could affect treatment planning and prioritization. Although some factors might play a more significant role in one patient's situation over another's, not having a comprehensive view when making the planning decisions could very possibly jeopardize the best interest of the patient and the overall outcome.

***III. Controversies in Treatment Methods:***

Early diagnosis and intervention are said to be critical to ASD patients.[25] However, sometimes symptoms, especially in the less severe and thus less obvious cases, can be overlooked before a child is sent to preschool, and special education programs might not be available until the child is in a public school system. Once a child is identified as in the spectrum, a variety of interventions can be done. They may include play-based therapies to learn things such as recognizing facial expressions, speech therapy, group sessions to develop social skills, and some might involve medications as well as physical therapy for related motor skill development. However, there are also controversies surrounding the treatment approaches themselves.

Some of the traditionally and commonly used therapies are being reconsidered. For example, while Applied Behavioral Analysis (ABA) therapy has been very popular for correcting autistic behavior over the past decades, some researchers and advocates criticize the way the treatment is done as abusive and oftentimes similar to treating humans like animals.[26] Some ABA therapy does involve forms of punishment as negative reinforcement to produce desired behavior, and these opponents argue that humans should not be forced into producing behavior to suit society's expectations. There is also a study that shows that ABA participants often develop Post Traumatic Stress Disorder well into their adulthood.[27] However, depending on how such therapies are conducted, there are also ABA therapists that use strictly positive reinforcement to produce desired results. Therefore, it is probably not the name of the therapy, but exactly how it is done under different circumstances that matters.

In addition, although ASD is found to have strong genetic links because they tend to run in families, the real causes are still quite unclear.[8,14] There are always forms of alternative treatment plans that some feel helpful but are never medically proven to be effective. Some of those alternative treatments


DOI: 10.36838/v4i6.8

(could simply be unhelpful for most people (such as a gluten-free diet), but others could be potentially harmful to the patients (such as chelation). Therefore, it is also important for the clinician and parents to be aware of these issues and make informed decisions.[14]

Last but not least, interventions for ASD often involve many parties who do not necessarily have the same levels of knowledge and agree on every stage of the patient's treatment plans. Education for parents is often also important because many of the interventions need to be accompanied with consistency at home to ensure their success. Once the child is in the school system, an IEP or 504 plan will greatly help with academic development, which involves the school's administrators, counselors, and teachers. For adolescents, it is especially important that employment and a career path are planned as high school graduates with ASD have the lowest employment rate (as low as 15%) among those with disabilities.[28]

Such career training might involve other organizations in the community and government assistance. Studies have also shown that ASD patients have higher rates of depression and anxiety.[14,15] Therefore, besides having a good support system at home, school, and the community, sometimes therapies or even medications across different disciplines are critical to ensure the mental well-being of such patients and continue to motivate them to develop their strengths and perform their best.

***IV. Whose Interest?:***

As can be seen, factors surrounding autism can be especially complex, and issues related to not only treatments but also how to give priority to different interventions targeting different areas with limited resources can be challenging. A question is often raised about whose interest is the most important to serve when setting priorities in treatments.

***A. Parents' Interests Often Prevail:***

It might be easy and intuitive to say that of course, it is the autistic individual's best interests that should always be served as the top priority, but sometimes this question is not that easy to answer. In certain cases, it is unclear what the best interest of the patient is. For example, for a severely cognitively compromised individual, it is often difficult to learn the best interest of the individual directly.[12] In such a case, the best interest can only be assumed based on the clinician's perceptions, which are heavily influenced by factors such as parents' major complaints. As another example, even for a patient whose IQ is within or even higher than the normal range, it would be very difficult for a young child to determine what is in their best interest. In that case, parents' best interest will likely be served, especially if priorities based on objective criteria are not presented to them before they make up their minds about their children's treatment plans.[12]

***B. Concerns with Focusing on Parents' Interests:***

Parents' preferences might or might not always be in the best interest of their child. For example, since parents are usually not medically trained, sometimes medications might feel extremely effective and preferred by a parent because it solves the most bothersome behavioral problem. In previous years when autism was less well-known to the general public, parents may have thought of sedation medications as an effective treatment, when it is not good for the patient in the long term.[15] As another example, sometimes parents might focus on the "atypical" parts of their children and believe it is the top priority in treatment. These atypical behaviors, such as avoiding eye contact or RRBs (restricted, repetitive behaviors) like stimming, can be socially embarrassing for the parents and might be the things that bother the parents the most, so they see them as a priority to eliminate. However, those might not be a priority for the best interest of the patients. Studies have shown that forcing eye contact can be extremely uncomfortable and even traumatic to autists,[29] and stimming is often beneficial for self-regulating.[13] In those cases, time spent to correct these behaviors can actually be counter-productive to the patient's well-being and not to their best interest because such attempts to mask or pretend to be neurotypical can be tiring, can cause self-esteem issues and can lead to depression and anxiety.[30] In fact, studies have shown that suicide is much higher among the ASD population. Although no study has yet statistically proven that the high rate is directly linked to masking behaviors, it does show the abnormally high level of stress that comes from being on the spectrum and trying to fix one's behavior to appear to be more normal.[20] When that is the case, instead of focusing on "fixing" atypical but non-harmful behavior, spending time developing the child's strengths will likely be more productive because it helps them gain self-esteem and in turn give the child higher motivations to do well in other areas, even if it's not a strength area.

In addition, if priorities are not first given from an objective perspective, such as patients' real needs and effective treatment plans that are research-based, but are more based on parents' intuition, some parents might see placing the child in a "normal" regular classroom, instead of keeping them in a special-education classroom, to be a top priority. Trying to place a child in a regular classroom where they do not belong could be traumatic mentally and socially. Additionally, pushing a child with ASD to perform alongside neurotypical peers in a regular classroom could mean spending an overwhelming amount of time and effort on academics and not placing enough emphasis on other areas, such as life skills. Although being included in regular classrooms might make parents feel better, "honest disagreements occur between individuals who argue, on a philosophical basis, that every child must be educated in the mainstream versus those who argue, on an empirical basis, that the child's needs should determine what setting is most appropriate."[15] In other words, with the best intentions, some parents might want their children to be in regular classrooms when in fact it might not be the best choice, and when it happens, the child's best interest is not being considered. To a different extreme, when an ASD child is especially talented in a certain way, or even to a point of potentially becoming a prodigy, some parents might focus too much time and effort on developing the child's special talent, instead of trying to reach a balance in terms of developing life skills or aiming to give the child a higher chance of gaining independence later in life.[31] This does not serve the best interest of the patient either.

In addition, it is worth noting the role of psychotherapy as part of the treatment plan. For example, many autistic individu

als are diagnosed with clinical depression, and this is especially common for adolescents with Asperger's, which are said to be "higher functioning" ASD cases.[14,15] Because most symptoms of autism cannot be changed with psychotherapy, it is an often-overlooked component of the treatment plan.[15] Parents are also likely to regard psychotherapy as something unnecessary because it does not usually solve any of the core symptoms of autism or eliminate any visible "problems."[15] However, as discussed before, many high-functioning autistic individuals are more prone to mental health issues such as depression and anxiety.[21,32] As a result, it is often in the best interest of the patients to have such psychotherapy, even though it does not make their autism symptoms "better."[21,32]

***C. When Parents' Interests Need to be Prioritized:***

Questions arise whether or not a parents' interest should ever be considered before the child's best interest. In general, the autistic individual's best interest should always be the priority. However, there are certainly circumstances under which the parents' best interest should be placed higher. For example, studies have shown that parents are often at "increased risk for depression or stress-related illness as a result of the unique problems inherent in living with a child with a serious disability."[14,33] One might argue that parents' mental health issues should be separated from the child's issues, instead mixing the parents' needs with the child's treatment needs. In a perfect world, that should probably be the case. However, sometimes it would be more practical to target a particular behavior that severely impacts parents' well-being, especially when a parent is unable or unwilling to seek additional medical help for themselves in the midst of the child's demanding treatment needs. After all, because parent involvement is oftentimes critical in the treatment process, the well-being of the parent directly makes a difference in the effectiveness of the treatment plans. Therefore, sometimes it might make sense to consider parent-preferred "behavioral improvement" a priority, at least temporarily, as it could possibly reduce stress and depression symptoms for the parents, making it possible for parents to be available and helpful during the course of the treatment.

***V. Future Research: A More Systematic and Objective Approach for Setting Up Intervention Priorities:***

When planning treatment for autistic patients, even for some autistic adults, parents' preference often plays an important role in determining what interventions will be conducted and the details like how and when they will be conducted. It is for obvious reasons, such as parents being the ones that spend the most time with these ASD patients, and since these patients might not be able to express their preferences, parents naturally become their spokesperson. In addition, parents are also the transportation providers for appointments and therapies, not to mention they often also need to continue to reinforce what has been learned during therapy sessions at home. Therefore, their opinions on intervention are often highly valued in the decision-making process. However, this paper challenges this intuitive approach which relies heavily on parents' preferences, and specifically on the assumption that parents are equipped to make the best choice for their autistic child.

As discussed, ASD is an overwhelmingly complex issue from many perspectives, so even though parents seem to be the ones that know their child best, they might not see the whole picture and have comprehensive knowledge of the field when they make intervention decisions for their child. As a result, this paper proposes the use of a more systematic and objective approach with parent education (patient education as well, if the patient is old enough and cognitively able to understand the content) as the first steps to generate intervention and treatment priorities. Future research should aim for developing parent education, in a format and language that is designed to be easily understandable to non-professionals, as well as tools designed to help draw out treatment priorities based on objective criteria, so that treatment planning will no longer be based on parents' intuition or major complaints. Of course, once the parents are presented with the result and explanations of such objective assessment that relies on research-based criteria instead of parents' intuition, communication should be done between the clinician, the parents, and if possible, the patients, so that then their informed preference will still be taken into consideration for setting up the actual treatment plan. A more comprehensive and objective approach that still involves the parents and the patients but equips them with enough knowledge to make informed decisions, will likely help pinpoint the most critical areas to work on, making the treatments more likely to benefit the patients.

***VI. Recommendations for Improved Communication and Decision Making in Treatment Planning:***

This paper would like to propose two specific ideas for future research that could help simplify the process of communicating such complicated issues surrounding ASD to parents and patients without much background knowledge.

***A. Education Program for Parents and Patients:***

An education program should be developed to explain the controversies and complexity of the issue surrounding ASD to parents and patients. There should be a basic and an elaborated version of the program, with the shorter version ranging from 2-4 hours that cover the most important issues, such as the basics of neurodiversity and strength-based approach, balancing between tackling parents' major complaints vs issues that benefit the patients directly, parents and patients' psychological health, and commonly discussed questions at different life stages. Such a program aims to give parents and patients a science-based quick overview of what is important but might not be very intuitive to them, for example, when focusing on what bothers them the most might not benefit the patient the most. Also, a longer program that aims to provide more knowledge and resources on a continuous basis for parents and patients should be made available, especially to those who are able to invest time to better equip themselves with higher levels of knowledge to make more informed decisions in their future treatment plan modifications. This could also have a ripple effect in the community, as some parents may have the time to pursue more in-depth education and can share advice and resources with other families. Given the complexity of autism and recent advances in research, there is so much potential to develop resources based on the data that exist and the impor


DOI: 10.36838/v4i6.8

tance of passing this knowledge to the decision makers (e.g., parents) in a structured format that is easy to understand.

Depending on available funding and practicality, such a program can be potentially made into quite a few different formats. It could be a series of sessions offered by clinicians to their own patients' parents, community workshops organized by practitioners in the same geographical area with or without a live discussion and support component, or even Zoom classes hosted by trained professionals across a large geographical area that can be made readily available to parents of newly diagnosed ASD patients. If resources are limited, a program as simple as a link to a series of online videos provided to the parents could also work, although it might not be as effective as having direct guidance from a live professional who would be able to address questions. Bear in mind, however, that delivering such education to the parents in a timely manner before determining a treatment plan should be an important goal of the program.

***B. Detailed Categorization of Patients' Profile:***

Since the term "on the spectrum" is such a broad term that covers a huge variety of complicated symptoms, not to mention other commonly seen issues surrounding it, it will be helpful for some kind of a category code system to be developed to help parents and patients get a more concrete sense of their overall situation. First, a chart with letters and numbers with the corresponding levels of conditions for each factor described should be established. For example, a series of letters and numbers could be used to represent not only where on the "spectrum" the patient is in terms of related criteria such as verbal and cognitive abilities and areas of strengths, but also other factors such as mental health issues, other learning differences, medical conditions, and physical disabilities. A patient's combined condition could be summarized with a series of letters and numbers such as "KEDSTVA235Z…" In addition, each combination of long codes ("KEDSTVA235Z…") should be identified as a category; for example, "KEDSTVA235Z…" could be classified as the Type 17 category. Although this approach does not intend to replace more personalized evaluations of the patient's overall conditions, a quick categorization not only makes the abstract term "on the spectrum" more concrete and gives the patient a unique profile, but it also in a way highlights all the important factors for the physician, parents, and patients to consider during the process of identifying such a code and category, ensuring that none of those important factors will be overlooked in the treatment decision process. Furthermore, once such a category code system is established, one potential benefit is that it may help parents find specific resources or communities for support. More importantly, it will make comparing cases easier in research, and more focused research could be done for different categories of patients, which will potentially help develop useful patterns in future treatment priorities.

Please note that this paper does not propose that an objective assessment should replace parents' opinions completely, but simply strongly suggests that parents should make many better-informed decisions together with the patients and the clinicians, rather than basing their decisions on what seems to bother them the most. After such an educational program and assessment tool are developed and used, clinicians should continue to take parents' support as a priority, especially given the success of interventions still often depends largely on their involvement.

## Conclusion

Families and clinicians often have the best intentions in mind when dealing with ASD treatment planning. However, due to the complicated nature of neurodiversity, especially issues related to autism, the best intentions do not always translate into treatment priorities that are the best for the patient when decision makers are not aware of all the relevant factors. Therefore, it is critical for an education program to be developed to make sure that such messages are passed to them before they make the treatment choices with their clinicians. However, since parents are unlikely to be professionals in the field, an education program with an easy-to-understand language and format, as well as an appropriate length, should be the key to the success of such a program. In addition, this paper also suggests that some type of systematic evaluation of a patient's unique situation should be developed, such as one with codes and categories, so that the seemingly complicated factors can be better summarized into a simpler format, not only for the families to better understand their overall situations and get the appropriate support but also for developing future research in treatment planning for different types of patients with similar needs.

## References


1. Kapp, S. K. *Autistic Community, and the Neurodiversity Move ment*: *Stories from the Frontline*; 2020.
2. Jaarsma, P.; Welin, S. Autism as a Natural Human Variation: Re flections on the Claims of the Neurodiversity Movement. *Heal. Care Anal.* **2012**, 20 (1), 20–30. https://doi.org/10.1007/s10728-011-0169-9.
3. Bennett, E.; Heaton, P. Is Talent in Autism Spectrum Disorders Associated with a Specific Cognitive and Behavioural Phenotype? *J. Autism Dev. Disord.* **2012**, 42 (12), 2739–2753. https://doi.org/10.1007/s10803-012-1533-9.
4. Cosden, M.; Koegel, L. K.; Koegel, R. L.; Greenwell, A.; Klein, E. *Strength-Based Assessment for Children With Autism Spectrum Disorders*; **2006**.
5. Woods, R. Exploring How the Social Model of Disability Can Be Re-Invigorated for Autism: In Response to Jonathan Levitt. *Dis abil. Soc.* **2017**, 32 (7), 1090–1095. https://doi.org/10.1080/09687599.2017.1328157.
6. Kimberly E. Bodnera, Diane L. Williams, C. R. E.; J., and N.; Minshew. A Comparison of Measures for Assessing the Level and Nature of Intelligence in Verbal Children and Adults with Autism Spectrum Disorder. *Res Autism Spectr Disord.* **2014**, 8 (11), 1434–1442.
7. E., F. Epidemiology of Autism and Related Conditions. Autism Pervasive Dev. *Disord.* **1998**, 32–63.
8. Aman, M.G. Treatment planning for patients with autism spectrum disorders. *J. of Clin. Psychiat*. **2005**, 66, 38.
9. Jon Baio, N. C. on B. D. and D. D. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm.
10. Kapp, S. K.; Gillespie-Lynch, K.; Sherman, L. E.; Hutman, T. Deficit, Difference, or Both? Autism and Neurodiversity. *Dev. Psychol*. **2013**, 49 (1), 59–71. https://doi.org/10.1037/a0028353.

11.Rodger, S.; Braithwaite, M.; Keen, D.; Research Online, G.; Rod ger, S.; Braithwaite, M. Early Intervention for Children with Au tism: Parental Priorities Author Copyright Statement Link to Pub lished Version Early Intervention for Children with Autism: Parental Priorities; 2004.
12.Leadbitter, K.; Buckle, K. L.; Ellis, C.; Dekker, M. Autistic Self-Advocacy and the Neurodiversity Movement: Implica tions for Autism Early Intervention Research and Practice. Front. *Psychol.* **2021**, 12 (April), 1–7. https://doi.org/10.3389/fpsyg.2021.635690.
13.Kapp, S. K.; Steward, R.; Crane, L.; Elliott, D.; Elphick, C.; Pellicano, E.; Russell, G. 'People Should Be Allowed to Do What They like': Autistic Adults' Views and Experiences of Stimming. *Autism* **2019**, 23 (7), 1782–1792. https://doi.org/10.1177/1362361319829628.
14.Volkmar, F.; Siegel, M.; Woodbury-Smith, M.; King, B.; Mc Cracken, J.; State, M. Practice Parameter for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorder. J. Am. Acad. Child Adolesc. *Psychiatry* **2014**, 53 (2), 237–257. https://doi.org/10.1016/j.jaac.2013.10.013.
15.Volkmar, F.; Cook, E. H.; Pomeroy, J.; Realmuto, G.; Tanguay, P.; Bernet, W.; Dunne, J. E.; Adair, M.; Arnold, V.; Beitchman, J.; Scott Benson, R.; Bukstein, O.; Kinlan, J.; McClellan, J.; Rue, D.; Shaw, J. A.; Sloan, E.; Kroeger, K. D.; Bristol-Power, M.; Fed er, J.; Filipek, P.; Harris, S.; Lord, C.; Mesibov, G.; Paul, R.; Rogers, S.; Schopler, E.; Schreibman, L.; Stone, W.; Wing, L. Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and Other Pervasive De velopmental Disorders. *J. Am. Acad. Child Adolesc. Psychiatry* **1999,** 38 (12 SUPPL. 1), 32S-54S. https://doi.org/10.1016/S0890-8567(99)80003-3.
16.O'Reilly, M.; Rispoli, M.; Davis, T.; Machalicek, W.; Lang, R.; Sigafoos, J.; Kang, S.; Lancioni, G.; Green, V.; Didden, R. Func tional Analysis of Challenging Behavior in Children with Autism Spectrum Disorders: A Summary of 10 Cases. *Res. Autism Spectr. Disord*. **2010**, 4 (1), 1–10. https://doi.org/10.1016/j.rasd.2009.07.001.
17.Bradley, L.; Shaw, R.; Baron-Cohen, S.; Cassidy, S. Autistic Adults' Experiences of Camouflaging and Its Perceived Impact on Mental Health. *Autism in Adulthood.* **2021**, 3 (4), 320–329. https://doi.org/10.1089/aut.2020.0071.
18.Assouline, S. G.; Foley, M.; Colangelo, N. N.; O'Brien, M. The Par adox of Giftedness and Autism The Paradox of Giftedness and Autism Packet of Information for Professionals (PIP)-Revised (2008) *The Connie Belin & Jacqueline N. Blank International Center for Gifted Education and Talent Development*; **2008**.
19.McFadden, J. Identifying and Supporting Twice-Exceptional Stu dents with Autism Spectrum Disorder (ASD). *J. Educ. Leadersh. Action* **2017**, 4 (2).
20.Cassidy, S.; Bradley, L.; Shaw, R.; Baron-Cohen, S. Risk Mark ers for Suicidality in Autistic Adults. *Mol. Autism* **2018**, 9 (1). https://doi.org/10.1186/s13229-018-0226-4.
21.Spain, D.; Happé, F. How to Optimise Cognitive Behaviour Ther apy (CBT) for People with Autism Spectrum Disorders (ASD): A Delphi Study. *J. Ration. - Emotive Cogn. - Behav. Ther.* **2020**, 38 (2), 184–208. https://doi.org/10.1007/s10942-019-00335-1.
22.Christon, L., and Myers, B. Family-Centered Care Practices in a Multidisciplinary Sample of Pediatric Professionals Providing Autism Spectrum Disorder Services in the United States. Res. *Au tism Spectr. Disord*. **2015**, 20, 47–57.
23.Taylor, B. A.; Fisher, J. Three important things to consider when starting intervention for a child diagnosed with autism. *Behavior Analysis in Practice*. **2010**, 3(2), 52.
24.Lindgren, S.; Wacker, D.; Schieltz, K.; Suess, A.; Pelzel, K.; Ko pelman, T.; Lee, J.; Romani, P.; O'Brien, M. A Randomized Controlled Trial of Functional Communication Training via Tele health for Young Children with Autism Spectrum Disorder. *J. Autism Dev. Disord*. **2020**, 50 (12), 4449–4462. https://doi.org/10.1007/s10803-020-04451-1.
25.Razjouyan, K.; Miri, M.; Zarei, M.; Farhangdoost, H.; Tavakoli, S. Study of the Effectiveness of Comprehensive, Timely, and Fami ly-Oriented Interventions in Reducing the Symptoms of Autism in Children. *J. Fam. Med. Prim. Care* **2020**, 9 (6), 2945. https://doi.org/10.4103/jfmpc.jfmpc_947_19.
26.Kirkham, P. 'The Line between Intervention and Abuse' – Autism and Applied Behaviour Analysis. Hist. *Human Sci*. **2017**, 30 (2), 107–126. https://doi.org/10.1177/0952695117702571.
27.Kupferstein, H. Evidence of Increased PTSD Symptoms in Autis tics Exposed to Applied Behavior Analysis. *Adv. Autism* **2018**, 4 (1), 19–29. https://doi.org/10.1108/AIA-08-2017-0016.
28.Chen, J. L.; Leader, G.; Sung, C.; Leahy, M. Trends in Employ ment for Individuals with Autism Spectrum Disorder: A Review of the Research Literature. *Rev. J. Autism Dev. Disord*. **2015**, 2 (2), 115–127. https://doi.org/10.1007/s40489-014-0041-6.
29.Hadjikhani, N.; Åsberg Johnels, J.; Zürcher, N. R.; Lassalle, A.; Guillon, Q.; Hippolyte, L.; Billstedt, E.; Ward, N.; Lemonnier, E.; Gillberg, C. Look Me in the Eyes: Constraining Gaze in the Eye-Region Provokes Abnormally High Subcortical Activation in Autism. Sci. Rep. **2017**, 7 (1). https://doi.org/10.1038/s41598-017-03378-5.
30.Arwert, T. G.; Sizoo, B. B. Self-Reported Suicidality in Male and Female Adults with Autism Spectrum Disorders: Rumination and Self-Esteem. *J. Autism Dev. Disord.* **2020**, 50 (10), 3598–3605. https://doi.org/10.1007/s10803-020-04372-z.
31.Feldman, D.H. Child Prodigies: A Distinctive Form of Giftedness. *Gifted Child Quart*. **1993**, 37(4), 188-193.
32.Lai, M.-C.; Kassee, C.; Besney, R.; Bonato, S.; Hull, L.; Man dy, W.; Szatmari, P.; Ameis, S. H. Prevalence of Co-Occurring Mental Health Diagnoses in the Autism Population: A Systematic Review and Meta-Analysis.
33.Marcus LM, K. L. S. E. Working with Families. Handb. *Autism Parasite Developmental Disorder.* **1997**, 631–649.

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DOI: 10.36838/v4i6.8