

At a Crossroads—Reconsidering the Goals of Autism Early Behavioral Intervention From a Neurodiversity Perspective

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The neurodiversity perspective posits that each person has a unique brain and a unique combination of traits and abilities and asserts that many challenges faced by autistic individuals stem from a lack of fit between the characteristics of autistic people and society's expectations and biases. The neurodiversity movement is akin to a civil rights movement. Among its goals are reducing stigma, increasing accessibility, and ensuring that autistic individuals' voices are represented in decisions about autism research, policy, and clinical practice. The neurodiversity movement is having a growing influence on the scientific community, as evidenced in the recent pause in a large autism genetic study based on concerns raised by the autism community. 1 It is also affecting autism practitioners as, increasingly, parents are expressing reservations about enrolling their child in early intervention programs, citing concerns that such programs do not value neurodiversity and, instead, prioritize changing their child's behavior to fit neurotypical norms.

The neurodiversity perspective is challenging autism researchers and interventionists to reconsider what should be the goals of early intervention, and specifically, whether the goal of intervention should be preventing, or promoting the loss of, an autism diagnosis. The concern raised is that this goal carries the implicit assumption that the objective of early behavioral intervention is to make autistic individuals appear indistinguishable from their neurotypical peers.² The need to clarify what constitutes a successful outcome for early intervention is underscored by recent advances in identifying autism at increasingly younger ages. Detection of early signs of autism in infants and autism biomarkers based on eye tracking, electroencephalogram, and magnetic resonance imaging are enabling early intervention to begin before an autism diagnosis is made.³ Although starting intervention as early as possible has been found to improve outcomes, the goal of preempting or losing an autism diagnosis is distinct from a goal of improving the child's language, adaptive behavior, daily living skills, and functional communication skills. It is also distinct from the important intervention goals of helping ameliorate anxiety, aggressive behaviors, meltdowns, and self-injury, which can significantly affect quality of life and often lead to more restrictive educational and living environments. Such goals are worthwhile for all children diagnosed with a developmental disability.

What evidence do we have that preventing or losing an autism diagnosis is associated with improved long-term outcomes and quality of life for autistic individuals? When the loss of an autism diagnosis has been documented later in life, such individuals often struggle with other psychiatric conditions. A recent longitudinal study of diagnostic stability in autistic individuals

found that "good" outcomes based on independent living, employment, and friendships were achieved by adults who lost an autism diagnosis but also by those who gained or retained a diagnosis. 5 Several studies have shown that masking or camouflaging autistic traits has been associated with higher rates of mental health conditions, such as anxiety and depression.⁶ Some autistic behaviors, such as self-stimulatory behaviors, have been found to serve a self-regulatory function for autistic individuals. As such, it is important to consider whether the purpose of preventing or losing an autism diagnosis through early intervention is because autistic traits, such as self-stimulatory behaviors, are stigmatizing in a society that fails to accept neurodiversity. If so, if we are a society that values diversity, the onus should be on society to change, not the autistic individual.

In addition to promoting language, communication, and adaptive behavior, a key objective of early autism intervention is to facilitate social interaction and relationships. During naturalistic developmental behavioral interventions, ⁷ promoting reciprocal social interaction involves learning and changes on the part of both partners who participate in the interaction, rather than only the autistic child. The parent or clinician needs to understand what social activities the autistic child prefers and how to successfully join with the child in those activities. They may need to adjust the structure of the interaction to ensure that the child is not overstimulated and learn how to interpret cues that indicate that the child is initiating an interaction or finished with an interaction, which are often different than the cues used by a neurotypical child. A key point is that a positive reciprocal social interaction with an autistic child might look different than an interaction with a neurotypical child. Some children may prefer briefer interactions or alternating face-to-face interaction with bouts of parallel play. Successful communication will also look different for many autistic individuals. Some will use a keyboard or pictures to communicate. From this perspective, an optimal outcome for any autism intervention can be defined as an enhanced quality of life which for most people means living as independently as possible, making choices about one's own life, developing satisfying social relationships, communicating one's needs and desires, and applying one's talents and interests in a meaningful and productive manner. These goals are entirely consistent with retaining an autism diagnosis.

Looking ahead, autism researchers can take steps to promote neurodiversity-affirming early intervention practices, which can help address the concerns of the autism community and allay the apprehensions about early intervention we are hearing from parents and self-advocates. This approach aligns with participatory research principles and the neurodiversity movement's

slogan "nothing about us without us." First, clinician training curricula can include writings from autistic individuals on topics such as sensory experiences to ensure that autistic lived experiences are appreciated and incorporated into clinical practice. Second, efforts can be made to recruit autistic researchers to the field so that the perspectives of autistic individuals are considered in the design of intervention models and outcome measures. Third, intervention methods can be used that encourage the child's expression of their needs and preferences and the ability to make choices, as these skills are foundational for self-advocacy and enhance the child's enjoyment and motivation to participate in intervention. Finally, practitioners can ensure that intervention goals involve shared decision-making with the input of both the parent and the child (insofar as possible) and that these goals prioritize the child's quality of life.

Neuroscience has underscored the plasticity of the brain in early development and suggests that expanding the repertoire of skills of an autistic child to include social reciprocity, language and communication, self-regulation, and adaptive skills through early intervention is fully compatible with encouraging autistic strengths and teaching self-advocacy skills. In the future, the use of a strengths-based approach to define outcome measures that emphasizes the unique abilities of each autistic individual will promote positive self-esteem and potentially help reduce the high rates of depression and anxiety experienced by autistic individuals. The neurodiversity perspective urges the field of autism intervention research to reframe the goal of early intervention as the promotion of a diversity of adaptive skills and traits that will lead to a fulfilling life as an autistic individual.

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REFERENCES

- 1. Sanderson K. High-profile autism genetics project paused amid backlash. *Nature*. 2021;598 (7879):17-18. doi:10.1038/d41586-021-02602-7
- 2. Ne'eman A. When disability is defined by behavior, outcome measures should not promote "passing". *AMA J Ethics*. 2021;23(7):E569-E575. doi:10.1001/amajethics.2021.569
- 3. MacDuffie KE, Estes AM, Harrington LT, et al. Presymptomatic detection and intervention for autism spectrum disorder. *Pediatrics*. 2021;147(5): e2020032250. doi:10.1542/peds.2020-032250

- 4. Orinstein A, Tyson KE, Suh J, et al. Psychiatric symptoms in youth with a history of autism and optimal outcome. *J Autism Dev Disord*. 2015;45(11): 3703-3714. doi:10.1007/s10803-015-2520-8
- 5. Elias R, Lord C. Diagnostic stability in individuals with autism spectrum disorder: insights from a longitudinal follow-up study. *J Child Psychol Psychiatry*. 2021. doi:10.1111/jcpp.13551
- **6**. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clin Psychol Rev.* 2021;89:102080. doi:10.1016/j.cpr.2021.102080
- 7. Schreibman L, Dawson G, Stahmer AC, et al. Naturalistic developmental behavioral interventions: empirically validated treatments for autism spectrum disorder. *J Autism Dev Disord*. 2015;45(8):2411-2428. doi:10.1007/s10803-015-2407-8