

VIEWPOINT

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Reframing Optimal Outcomes in Autism

For decades, autism (or autism spectrum disorder) has been described as a neurodevelopmental disorder diagnosed in early childhood. Genetic and environmental studies provide evidence for autism's variable causes,¹ while intervention and natural history studies suggest substantial heterogeneity in clinical presentation, response to treatment, and developmental outcomes.² More recently, autism has also been described using the framework of neurodiversity—that is, autism as an example of diversity in a wide range of brains, none of which are considered normal and all of which are different.³

At first glance, the 2 views of autism—disorder vs neurodiversity—appear to be mutually exclusive and completely at odds. However, both views seem to accept the notion that autism is neurodevelopmental—that is, autism is characterized by variation in brain function and development. We decided to build on that common ground as we begin to rethink progress and outcomes in children with autism.

Traditionally, research has focused on identifying risk factors and mechanisms associated with autism. However, emerging scientific literature discusses the varying trajectories and outcomes of children and youth with autism into the adolescent and early adult years.^{2,4} Fein and colleagues⁴ proposed the concept of optimal outcome to describe outcomes in a cohort of individuals with autism who, over time, stop meeting the diagnostic criteria for the disorder and function within an intellectual range that is considered to be normal.

In this Viewpoint we argue that, although the concept of optimal outcome (as defined by Fein et al⁴) may be useful in describing selected outcomes in a small proportion of individuals with autism, it is based on a rather limited approach to understanding the complex and variable ways that children with autism grow and develop. In an era when autism is conceptualized as a dynamic and diverse spectrum—across individuals, domains, and time—it is our opinion that the current, narrow definition of fixed optimal outcomes may be more relevant to the old categorical view of autism. Moreover, even if the specific definition seems to be (partially) compatible with the view of autism as a disorder, it is incompatible with the neurodiversity view of autism.

In a review on the topic of child mental health, Costello and Maughan^{5(p324)} defined the term *optimal outcome* as the “best possible outcome considering a child's history.” We find this general definition to be more suitable when describing the variable outcomes in children with autism. This specific definition does not limit the discussion of optimal outcomes to only children who meet extrinsically defined endpoints (dichotomous diagnostic thresholds) at the high end of the distribution. Rather, it allows for the use of the child's own history to examine intraindividual growth.⁶

To date, the field of autism has focused almost exclusively on highly verbal, cognitively able individuals to represent optimal outcomes. Overlooked are the many individuals with autism who are able to communicate despite their inability to use spoken language, or individuals with measurable intellectual disability but who function well in their chosen task or job. There are also many examples of individuals who make slow but steady improvements over their lifetime, and who, given initial expectations, are functioning optimally at later points in the life cycle. How might children who do not “lose their diagnosis” or meet traditional outcome indices qualify as showing an optimal outcome? We may want to reconsider these traditional indices and examine outcomes across a spectrum of domains. For example, an average or even high IQ score may not be a reflective indicator of an optimal outcome for an individual with autism who has no friends and is unhappy, anxious, or depressed.

Moving beyond a single snapshot of optimal outcome (or end point) toward a framework of varying and changing points along a pathway toward the optimal outcome allows for the study of progress in a way that is compatible with both views of autism—disorder and neurodiversity. The focus here is not on reaching certain milestones (often determined in relation to neurotypical populations) chosen by an external evaluator. Rather, the focus is on the child's progress (both rate and level of change) over time on goals and domains that are deemed meaningful by them (and their families). For example, one could potentially explore variability and change over time across multiple general aspects of life related to functioning, community engagement, and quality of life, as well as specific child development in the social, emotional, cognitive, moral, and physical domains. An additional layer of contextual variables—for example, family, school, and received interventions—can also be explored and taken into account when determining whether progress is in line with the goals and potential of the child, his or her family, and his or her environment.^{7,8} Most important, individuals and families living with autism need to be included in the conversation on identifying important and meaningful outcomes.

Although there is the suggestion from Fein and colleagues⁴ that optimal outcome status was achieved by both intensity (number of hours) and type of interventions delivered early in life, there may be false comfort in this finding. Many parents engage in similar intensity and types of interventions and yet their children do not achieve this optimal outcome. Nearly 50% of children receiving the type of intervention described in the study by Fein and colleagues⁴ (discrete trial training, a highly structured form of applied behavior analysis) do not achieve normative levels on standardized tests.⁹ The 50% of children who do not make fast gains may do so later in life (with different interventions) or they may

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have an optimal outcome that is identified and determined by other domains, beyond diagnostic symptoms and IQ.

Changing our notion of meaningful outcomes, and how and when those outcomes are measured, is a step toward an inclusive spectrum approach to understanding optimal outcomes in children with autism. The next step would be to consider how services and supports must change and adapt over time based on how children develop and respond to interventions.

How do we both examine and influence the developmental pathways of individuals with autism for optimal outcome? For example, good clinicians understand that most individuals need a sequence of interventions that change depending on the individual child's response. However, although informative in describing variability in autism trajectories, existing longitudinal studies do not explain how services and interventions influence those trajectories; they were simply not designed to do that. In autism intervention science, knowing when to change something, and what to change to, are important questions that remain unanswered.

After making great strides in describing progress in autism, we now find ourselves at a crossroads. Three major research advances can be useful when thinking about next steps: the cumulative knowledge from the first wave of prospective studies, the emergence of novel longitudinal and intervention methods, and the development of new assessment instruments that are sensitive to change. There is now considerable agreement among stakeholders that, no matter what view of autism we choose—disorder or neurodiversity—the next major challenge for researchers is to generate evidence that can help to personalize and adapt interventions to meet the diverse and changing needs of individuals and families living with autism.

Based on the aforementioned issues, opening the dialogue on reframing optimal outcome seems timely. We propose here a more comprehensive and inclusive definition of optimal outcome that captures diversity in individuals from across the autism spectrum, is based on within-individual growth over time, and describes progress on a wide range of variables and domains identified as meaningful by those living on the autism spectrum.

ARTICLE INFORMATION

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