Counseling Parents Regarding Prognosis in Autistic Spectrum Disorder

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ABSTRACT. A triaxial model for autistic spectrum disorder (ASD) is presented, incorporating age, degree of intelligence, and severity of autistic features. As the name implies, ASD can vary in degree of expression from minimal to profound. Furthermore, the symptoms of ASD change in predictable ways with the passage of time. For example, echolalia during early childhood may be replaced by verbal literalism and difficulty with verbal humor during later childhood or adolescence. The prognosis for children with ASD is governed by the joint impact of the degree of expression of ASD and the degree of developmental delay, if any. All combinations of ASD and intellect are possible (ie, severe ASD plus severe mental retardation, severe ASD plus normal general intelligence, and so forth). The relationship among these 3 parameters—severity of ASD, level of general intelligence, and change in symptom expression over time, is represented schematically as a 3-dimensional graph. The utility of this graph as a counseling tool, and as the basis for future research on the prognosis of ASD are discussed. Pediatrics 2000;105(5). URL: http://www.pediatrics.org/cgi/content/full/105/5/e65; autism, autistic spectrum disorder, pervasive developmental disorder, Asperger syndrome, developmental disability.

P A T I E N T S. Parents of the child with autistic spectrum disorder (ASD) commonly desire information regarding prognosis. In this article, I present a conceptual model, based on 2 decades of clinical experience, that I have found useful when introducing parents to the diagnosis of ASD and making preliminary statements about prognosis. This model does not enable the clinician to specify a given child’s outcome. Rather, it conveys an overall perspective of the range of expression of ASD and acts as a roadmap on which the parents may plot their own child’s progress over time. Although based primarily on my clinical experience, I believe this model also has the potential to serve as a frame of reference for formulating researchable questions regarding the epidemiology and prognosis of ASD, terminological issues, and the putative benefits of various therapeutic interventions.

The qualitative distortions of development in ASD are “atypical,” in the sense that there is no age for which they would constitute typical phenomena. For example, emergence of single words at 24 months of age would be indicative of speech delay (abnormally late, but typical behavior for a younger child); in contrast, absence of speech until 24 months of age, followed by the sudden appearance of echolalia and delayed echolalia would be considered atypical—there is no age for which this constitutes normative behavior. One parent of a child with ASD articulated this concept succinctly, describing her son as “off the beaten path.”

The model I use when counseling parents rests on 4 generally accepted premises:

- First, atypical development occurs along a spectrum from mild to severe, although differences of opinion remain between “lumpers” and “splitters” as to whether autism, pervasive developmental disorder, and Asperger syndrome should be classified as a continuous series or as separate entities with overlapping clinical features. Children with ASD display qualitative distortions in the development of language and ability to relate to others, plus a tendency toward dysfunctional, repetitious behaviors; these features can manifest in varying proportions and to varying degrees at different points along the spectrum. I use the term “atypicality” to refer to severity of expression of the core features of ASD.
- Second, phenotypic expression of ASD varies with age. Early follow-up studies of children with ASD tended to be skewed toward individuals at the more severely affected end of the spectrum, frequently with coexisting mental retardation (MR), suggesting relatively little change over time. Subsequent data, however, amply demonstrate that many children with ASD undergo significant qualitative change over time.
- Third, ASD of any degree of severity can occur in combination with any degree of general intelligence. I use the concept of general intelligence broadly, recognizing that the very concept of general intelligence begins to break down in children with ASD, who may have large discrepancies between nonverbal and verbal abilities. Young children with ASD are often untestable in the conventional sense, because they may be unaware that they are expected to imitate tasks presented by the examiner. I often rely on age of emergence of

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adaptive skills as a surrogate for formal IQ scores under such circumstances.

- Fourth, the long-term prognosis for any given child represents the joint impact of ASD and the child’s level of global cognitive ability or global cognitive delay. In my experience, the combined effect of global cognitive delay and ASD is almost multiplicative, rather than simply additive, in terms of the net decrement in functionality. This clinical impression is partly supported by the research literature: higher intelligence levels are associated with better outcome.1-14 However, I am not aware of any studies that have serially measured IQ and severity of autism as a way of developing an outcome model.

The foregoing principles can be represented graphically (Fig 1). First, I sketch in the 3 axes: age, intelligence, and atypicality. I begin with the x-axis, explaining that the x-axis to the left of the origin is dotted rather than solid because nobody’s age is less than zero. Next, I add the y-axis and finally the z-axis, with the diminishing severity of atypical features running into the plane of the paper. Once the parents have absorbed this frame of reference, I add 2 hypothetical children who represent polar opposites: a child with low IQ plus severely atypical features, and a child with high IQ and mildly atypical features.

As illustrated schematically in Fig 1, the child who presents with severe ASD plus MR tends to remain readily recognizable as having autism throughout life. In contrast, the child with mild to moderate ASD plus normal general intelligence tends to undergo predictable improvement with the passage of time. This process may progress to the point where the individual ceases to be readily recognizable as autistic, although subtle impairment remains. (The third edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association5 explicitly acknowledged this phenomenon, including the diagnostic category “Autism—Residual State,” to cover individuals who once met criteria for autism but no longer do. This term was removed from subsequent editions of the manual and is not presently in clinical use.) Teachers, acquaintances, or coworkers meeting an individual with mild, long-term residua of ASD for the first time as an older child, adolescent, or adult may be unable to mentally reconstruct the individual’s clinical profile as a preschool-aged child. This is the point at which the affected individual is at the greatest risk for harm from an educational system and society that do not recognize the individual’s continuing need for certain forms of social support. On rare occasions, the symptoms of ASD may disappear entirely.

When reviewing this diagram with parents, I explain that there are an infinite number of potential combinations of atypicality and global cognitive capability in addition to the 2 examples in Fig 1 (superior intelligence plus severe ASD, severe MR plus mild ASD, etc), and that I cannot specify their child’s location on the graph or their child’s long-term course based on 1 visit. However, over successive visits, we can begin to get an idea of where their child fits into the overall picture. Parents almost invariably find the foregoing presentation to be helpful. Although it does not offer a specific prognosis for their child, at least it gives them a logical framework within which they can place their own child’s development over time. (For parents who may be intimidated by a 3-dimensional graph, I use a more concrete metaphor: height and weight. “An individual may have any combination of height and weight. For example, someone can be tall and thin [like a basketball player], tall and heavy [like a football player], short and thin, or short and heavy. In the same way, someone can be very bright and mildly autistic, very bright and very autistic, etc…”)

In addition to serving as the basis for counseling with parents, this model also provides a conceptual framework for various researchable questions. First,
with respect to epidemiology and cause: Do children in each quadrant (high IQ and severe ASD; high IQ and mild ASD; low IQ and severe ASD; and low IQ and mild ASD) occur with equal frequency? Do the occupants of these 4 quadrants differ by underlying cause? Second, the diagnostic criteria for ASD generally reflect the clinical picture at the time of initial diagnosis (typically, late toddler or preschool), rather than during later childhood, adolescence, or adulthood. The 3-dimensional model underscores the need for developing quantifiable, socially relevant diagnostic criteria for older children and adults with ASD.16,17 Third, with regard to prognosis: Implicit in the model is the concept that there is a natural history to ASD, regardless of intervention. Over the years, various therapies for ASD have enjoyed their moment of popularity. There is little evidence, however, that the prognosis is much different today than it was 20 or 30 years ago, if one corrects for the severity of ASD and cognitive impairment at the time of initial diagnosis.

The model I have presented underscores the need for long-term follow-up data with serial quantification of the severity of ASD and IQ. Currently available measures focus primarily on making the initial diagnosis, rather than quantifying the severity of ASD over time. However, instruments such as the Childhood Autism Rating Scale,18 the Autism Diagnostic Interview-Revised,19 or the Autism Diagnostic Observation Schedule20 could be used or adapted to this purpose. Longitudinal data on IQ and severity of ASD would transform the above model from a conceptual scheme to a clinical tool by which to predict outcome for individual children and to correct for the anticipated degree of improvement when attempting to assess the efficacy of an intervention technique.

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