

Preface

Until recently, autism has been considered by many as a hopeless, incurable, and absolute condition. Now, however, research suggests that intensive behavioral intervention, begun when a child is between 2 and 5 years old, can have a significant and lasting positive impact. This intervention leads to improvement in virtually all children, and in some cases it leads to complete eradication of any sign of the disorder. While behavioral intervention is also the treatment of choice for older children and adults with autism, research shows that its potential for dramatic improvement is greatest with young children. It is that positive research that inspires and focuses this book.

What is autism? For some time autism has been considered a pervasive developmental disability. It is presumed to be a biological disorder of brain development, not an emotional disorder that results from parental behavior or family dysfunction. Exactly what causes the abnormal brain development is not known at this time—in part because autism has not yet been reliably detected by brain scans or other medical tests. At present, autism is diagnosed by direct observations of a child's behavior. It is estimated to affect 5–15 of every 10,000 children born worldwide, regardless of race, culture, parental characteristics, or family socioeconomic status. Boys are affected about three to four times more often than girls (Rapin, 1991; Schreibman, 1988).

The label *autism* is applied when a qualified professional (usually a licensed psychologist or a physician) determines that before the age of 3 years, a child displays a number of marked deficits and excesses in several behavioral domains: communication, symbolic or imaginative activities (such as play), reciprocal social interaction, and interests and activities. Within each of these areas, any of several abnormalities may be observed. Communication impairments, for example, may include no useful vocal or nonvocal communication, speech that is repetitive or nonsensical, or well-developed speech that is not used socially (e.g., to engage in normal conversation). Development of play behavior may be severely delayed. If it develops at all, it usually lacks spontaneity, variety, and social components. In fact, all social interactions are often impaired to the point that the individual seems largely uninterested in and unresponsive to other people. The range of interests and activities may be very restricted. Often, a few stereotyped patterns of behavior are repeated over and over. Other problems that are not unique to autism but of-

ten accompany it include attentional problems; abnormally high- or low-activity levels; disruptive behavior (e.g., tantrums, shrieking); destructive behavior toward property, others, or self; abnormal responses to sensory stimuli; seizures; and apparent insensitivity to physical dangers and pain. Many children with autism also have great difficulty learning. A small percentage score in the normal range on tests of cognitive abilities, but 75%–80% function in the mild to severe range of mental retardation (Rapin, 1991).

A diagnosis of autism should be based on extensive direct observation of the child and comprehensive interviews with family members and other caregivers. A number of behavioral checklists can help differentiate autism from other childhood disorders (e.g., mental retardation without autism, specific language disorders, schizophrenia), and some standardized assessments can help define the extent of developmental delay or deviation. However, all psychological, educational, and language tests are subject to problems of reliability in identifying autism (American Psychiatric Association, 1994; Rapin, 1991; Rutter & Schopler, 1987). Moreover, the wide range of behaviors associated with autism and the individuality of each child's behavioral profile make a *typical* case somewhat difficult to define. In other words, the presence or absence of single behaviors cannot definitively rule out or confirm autism, although clichés, caricatures, and overgeneralizations about autism abound. To give but one example of such an overgeneralization, public perception seems to be that all autistic children rock their bodies back and forth. One possible result of this perception might be that a mother and father may have concerns about their child, but delay seeking a diagnosis because they have read that autistic children rock, and their child does not happen to rock.

To further complicate these difficulties, many pediatricians, to whom parents first turn when they suspect a problem in their child, tend to not recognize the early symptoms of the disorder. Many parents of autistic children report to us that their pediatrician told them to "Wait and see. He'll grow out of it."

When a diagnosis is finally made, it is usually made by one or several specialists, as noted above. It is not unusual, however, for different professionals to label the disorder differently, as in the case where one professional says "autism," the next says "pervasive developmental disorder with autistic features," and the next says "pervasive developmental

disorder, not otherwise specified." While some of these labels may make parents feel better, no hard evidence exists that any of these different labels should be taken any less seriously than the term *autistic*. There seems to be an understandable tendency for many parents and professionals to want to avoid, at all costs, the word *autistic*. A parent may say, for instance, "Dr. X says my child is not autistic, she only has autistic tendencies," or "she only has pervasive developmental disorder." However, if the parent is encouraged to then make therapeutic decisions based on the impression that the child's condition is very mild or transient, those decisions may not be optimal for the child.

Taken together, it is obvious that all of these diagnostic difficulties can (and often do) lead to problems of delay, denial, confusion, or psychological turmoil for parents. Unfortunately the question of how to diagnose and label a child is only one of many controversial topics in the field of autism research and treatment. Another is the optimal age for such a diagnosis, and the optimal age to begin treatment. Some professionals refuse to confer a diagnosis until the child is 3 or 4 or even 5, at which point they may finally label him or her "autistic." Meanwhile, 1, 2, or 3 years may have passed, years in which the child could have been engaged in a structured, intensive treatment program.

If parents receive several vague, placating, or conflicting opinions from different diagnosticians, but continue to have grave concerns over a child's development, they might consider beginning a program of early intervention anyway. This may be preferable to waiting for everyone to agree on the diagnosis and losing valuable time in the process.

It is our hope that this manual will offer some assistance to parents, and to the professionals who aid them, in the challenging task of making science-based treatment decisions, and procuring effective early intervention for children with autism.

—The Editors

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