

Preface

“Now, 12 years later, following our son’s diagnosis of autism and an endless series of early interventions, our son still speaks in two- to three-word sentences. He still obsessively flips sticks and other objects while pacing the room to control what I think must be a storm in his head. He is, however, a lot bigger.”

—ROBERT WARD, father of an adolescent with autism

These words reflect the reality that, despite early intervention efforts, some children with autism may require lifelong intervention. The behaviors that were once tolerable in a small child with autism can become more socially intrusive and intolerable as the child matures in age and physical size. Of concern is that individuals with autism can often require lifelong intervention (e.g., Howlin, Goode, Hutton, & Rutter, 2004). This appears to be the case particularly for those individuals with significant impairments in areas such as intelligence, expressive language, and social skills (Gillberg, 1991; Murphy et al., 2005). The behavioral, emotional, and dependency issues of this population are likely to become of paramount concern for communities as the increasing numbers of identified children with autism grow up (Chakrabarti & Fombonne, 2005).

Children with autism differ in the degree of impairment in core diagnostic symptoms (social, communication, and behavioral) and associated symptom impairments (e.g., intellectual and adaptive ability). An

estimated 70–75% of this population is also diagnosed with mental retardation, with approximately 50% of individuals lacking functional communicative speech (Happé & Frith, 1996). The heterogeneity of impairment in this population likely contributes in large part to the variability documented in treatment outcome research, with some children making great progress and others making little, regardless of the type and intensity of intervention (e.g., Gabriels, Hill, Pierce, Rogers, & Wehner, 2001; Howlin, Goode, Hutton, & Rutter, 2004). However, research indicates that the most significant predictor of later outcome appears to be the level of intellectual functioning in childhood (e.g., Lord & Bailey, 2002).

The goal of this book is to comprehensively address one of the most challenging aspects of the autism population: the needs of school-age children and adolescents with autism as they prepare for adulthood. Since the majority of individuals with autism are severely impaired and may require lifelong supports, the focus of the following chapters is on this population at a time when professionals can assist families to move beyond the stage of early intervention and consider how the fundamental difficulties of the child's autism diagnosis may interfere with such aspects of their lives as integrated classroom settings, pubescence, and preparation for adulthood.

The individual chapters are organized within the perspective of a multisystemic therapy model derived from family systems theory. This model views a circular process of systems change needed to resolve the problems of the individual and considers the interconnections among the individual, family subsystems, and broader systems of community service (Cunningham & Henggeler, 1999). The onset of adolescence and puberty in individuals with autism is a critical period that brings with it changes in the needs of the individual and family. "As the child [with a disability] grows older, the developmental steps of each member of the family are thrown off balance": parents continue to be tied to a child who requires extensive support and supervision (Riley, 1994, p. 142). Other changes that occur during adolescence, affecting both the individual with autism and the family, are the types and amounts of community services available. Professionals and therapeutic services may no longer be as easy to access or may not consist of a coherent network compared with early intervention services. In response to these issues, the chapters in this book are divided into three major sections, based on the interconnected systems (individual, family, and community) with which professionals are faced when working with the population of more severely impaired school-age children and adolescents with autism.

PART I: THE INDIVIDUAL WITH AUTISM

The challenging behaviors of individuals with intellectual disabilities, including those with autism, can be an important factor in determining the quality of life for the individual and the levels of caregiver stress (e.g., Emerson, 2003; Hastings, 2002). Chapters 1 through 6 focus on the challenges specific to more severely impaired individuals with autism, with an emphasis on illuminating the multiple ways to explain behavior challenges, along with intervention suggestions to address these challenges. The chapters cover behavioral and medical issues common to this particular group, as well as the important topics of sexuality, communication, sensory-motor issues, and social skills.

PART II: FAMILY AND CAREGIVERS OF THE INDIVIDUAL WITH AUTISM

Chapters 7 through 9 shift the focus from children and adolescents with autism to the needs of their families. Results of a pilot survey of problems reported by families of adolescents with autism revealed that the number one problem was not being able to take family vacations. Additional concerns include the unavailability of respite care, financial pressure, parents' emotional and physical health, and relationships among family members (DeMyer & Goldberg, 1983). The chapters in this section provide clinicians with practical advice on how to help families access services, while considering legal and future planning issues, and enjoy positive vacation and leisure experiences.

PART III: COMMUNITY ASPECTS OF INTERVENTION

The expectations of the community for individuals with autism will change as they enter school age and adolescence. There are also changes in schools, teachers, and other therapeutic support networks. It is likely that these changes contribute in some degree to increased problems in adolescence for this population (Gillberg, 1991). Chapters 10 through 13 go beyond the child and his or her immediate family to consider issues that involve the social community. This section provides a review of relevant clinical and theoretical research in the autism field, as well as offering hands-on suggestions and techniques to assist professionals in addressing child and caregiver needs. The chapters cover topics includ-

ing educational transitions, use of school consultants, treatment and intervention development, and forensic issues specific to this population.

In summary, the goal of this book is to provide professionals with an awareness of the issues pertinent to the individual with autism as he or she enters critical periods of development that include physical and sexual maturity. We hope that having such knowledge will allow professionals to make more useful recommendations for individuals with autism and to more effectively support families. Finally, the importance of developing a community network of support for these individuals as they grow older is reflected in the words of the same father whose words introduced this preface.

“In the early years my son’s condition was very isolating. Our family hunkered down—exhausted, afraid of scenes, one big exposed nerve. Over time, we have been able to develop a community, a rarity for many in modern America. It is our community of support made up of our family; other families facing the same challenges; committed friends; caregivers; and dedicated professionals. Parents of children with autism need that community of support. We can’t do it alone. Now my burdens are lighter, I trust more, things are easier. I realize there is a community that cares deeply about my son and my family. We are on the same team in an imperfect world in which my son has autism.”

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