

Preface

We have edited this collection of chapters on evidence-based and promising practices for adolescents and adults with autism spectrum disorders (ASD) for several key reasons. The recent tremendous explosion in cases of children with ASD is well known and documented throughout the world (Baron-Cohen et al., 2009; Baio, 2012; Gal, Abiri, Reichenberg, Gabis, & Gross, 2012; Kim et al., 2011). During the past 25 years or so there has been a concomitant increase in research and publications regarding the identification, assessment, and education of these children. This heavy focus on children is understandable given the promise of early identification and intervention. However, there remains a paucity of research and guidelines that focus on the issues that face adults with ASD.

One of us (Andy Bondy) served as a statewide director of a public school for students with ASD. Our primary challenge was to design a program that would confer an educational advantage to all students. In seeking to accomplish this goal, we asked ourselves a crucial question: What is the long-term goal of sending children with ASD to school? To answer this question, we engaged in many discussions with parents and professionals. We noted a common theme. Education in society at large aims to provide skills that lead to successful employment in the real world, living independently away from one's parents, and being reasonably happy. We concluded that the goal of educating a student with ASD is exactly the same: to help him or her to get a good job in the community, to live away from home (even if support is still warranted), and to be reasonably happy. Thus all of our educational efforts had to conform to achieving these functional life goals in adulthood.

However, teaching communication, job skills, living skills, leisure skills, and so forth, would all be for naught if the posteducation community could not maintain and sustain these skills in the long term. For example, if a young woman learned to communicate about various wants and needs; acquired skills associated with shopping for food, preparing and cooking meals, and cleaning up; and then moved into a home in which all of these tasks were performed for her, it should not surprise us if these skills faded away over time. Conversely, if she had not acquired these skills in school, would adult service providers or parents teach these skills? These are some of the daunting challenges facing adults with ASD and their families. Yes, we need to identify and diagnose ASD early and provide an excellent education, but learning and growth do not stop at a particular age. This book is designed to offer hope and research-based guidelines about available strategies to help adults with ASD lead productive and happy lives.

We asked a number of leading researchers to write chapters on critical issues related to the well-being of adolescents and adults with ASD. Each set of authors was asked to review the current literature associated with a wide array of topics. In addition to reviewing key research, each chapter provides some examples of how specific features and strategies may influence a hypothetical case in terms of practical decision making. Some of the case studies provide detailed accounts of how real adults with ASD benefited from application of particular strategies; other case studies are hypothetical examples based on real-world experiences as detailed by the chapter authors.

Chapter 1, by Myles, Coffin, Owens, and Yantes, provides a lucid description of many of the characteristics and challenges faced by adults with ASD. The chapter begins with a review of many issues associated with communication and social interaction, including issues related to sexuality. The authors then describe some of the key factors related to the often unique sensory and motor issues among this group of individuals. Next, they present a review of various cognitive factors, including a discussion of executive function, central coherence, and emotional vulnerability. Chapter 2, by Pepa and Harris, focuses on ASD in the context of the family, especially the transition from the teenage years into adulthood. The authors review factors relating to the central role that families play in supporting their children with ASD in terms of service coordination, educational transition, employment, and potential residential transition. The chapter also provides guidance for finding social support on an ongoing basis. The last section of the chapter reviews research on a variety of family coping strategies and factors that may best help families through different types of transitions.

Chapter 3, by Wehmeyer and Zager, deals specifically with the transitional issues associated with leaving secondary school. The chapter begins

with a review of the federal requirements for transitional services, as well as college and career readiness issues. The authors provide clear guidelines for the elements considered essential to preparing an adequate transitional plan. These include clear suggestions for elements that should be included in a student's individualized education program (IEP). The chapter also reviews issues that may promote self-determination among adults with ASD. Finally, the authors provide guidance connected with transitioning into community living. Chapter 4, by Thierfeld Brown, Wolf, and Wenzel, addresses similar issues in postsecondary education. The chapter offers a comprehensive review of strategies that help those with higher functioning ASD cope with the academic and social demands that college may bring. The authors then discuss the supported education service model and how it can provide aid, often via coaching, for many adults with ASD. Another model that provides help with university issues is described in a model identified as Beyond Access. Finally, the authors provide examples of various uses of technology on campus that may help adults with ASD successfully navigate the requirements of a college education.

Chapter 5, by Aguirre, O'Neill, Rehfeldt, and Boyer, switches gears by looking at behavioral interventions that promote complex communication and social skills. The authors begin by reviewing components and research regarding behavioral skills training. They next review evidence of several specific strategies, including modeling, prompting, and reinforcement, with regard to specific skill acquisition for adults with ASD. A comprehensive review of the literature regarding script fading and peer-mediated instruction is offered, along with case examples. Finally, there is a fascinating discussion on the role of and strategies for promoting response variability, as well as the use of virtual environments, with this population. Chapter 6, by Lang and colleagues, also addresses issues related to communication, but from an augmentative and alternative communications (AAC) perspective. The chapter opens with a review of the term *communication* from both traditional and behavioral perspectives, including the importance of an analysis of the functional units of language. There ensues a description of AAC and a variety of modalities that may prove helpful in promoting functional communication, including manual signs, picture-exchange systems (e.g., the PECS), and speech-generating devices (SGDs). The authors provide a clear review of tactics and evidence on various modalities and strategies, including an overview of teaching strategies to promote acquisition and maintenance.

Chapter 7, by Tincani and Crozier, provides details of a broad approach to behavior intervention and life enhancement called positive behavior support (PBS). The chapter opens with a review of the historical context in which PBS was developed and how it is distinct from other approaches and orientations (including applied behavior analysis),

including its emphasis on prevention. Among the key factors associated with successful implementation of PBS are service delivery systems, autonomy and choice, and medical and health issues. The chapter concludes with a thorough review of primary, secondary, and tertiary support factors that must be addressed for comprehensive changes to occur and last.

Applied behavior analysis (ABA) is widely recognized as a strongly research-validated practice for young children with ASD, but for many years researchers and practitioners have successfully applied the principles and strategies of ABA to adults. Chapter 8, by Gerhardt, Garcia, and Foglia, gives an overview of ABA-based strategies for teaching a variety of skills to adolescents and adults with ASD, with an emphasis on adaptive and vocational skill domains. They review important considerations in arranging for stimulus control to teach skills to adults, as well as strategies for promoting generalization of skills in the community.

Chapter 9, by Travers and Whitby, looks specifically at the broad issue of sexuality and relationships. The opening section notes the rationale for sexuality education for people with ASD, and well as a review of their rights with regard to relationships, marriage, and parenthood. This discussion is complemented by noting the responsibility of society to report and prevent sexual abuse. The discussion continues by addressing sexual health and hygiene, self-determination, and specialized instruction. The core components of a wide-ranging sexuality education package are elucidated, including how cultural factors may influence training issues. The authors then review the extant literature on evidence-based practices regarding general and specific issues (including menstrual care and masturbation) and follow with case examples. In Chapter 10, Coyne and Fullerton provide information on the related topic of recreation and leisure. They review many studies regarding the overall importance of adults with ASD having fulfilling recreational and leisure skills and opportunities. The chapter includes a review of how factors associated with ASD may have an impact on the development and maintenance of recreational and leisure activities. This section is followed by a discussion of how incorporating an individual's strengths may inform the proper selection of leisure activities. The chapter ends with a detailed description of how to assess and plan the expansion of leisure activities.

Chapter 11, by Wehman, Targett, Schall, and Carr, focuses on the crucial issue of meaningful employment. The authors open with a frank discussion about the notoriously poor rate of community-based employment participation for adults with ASD. They review the general and research-based literature on this topic. From that review, the authors provide a number of promising practices that should help improve the likelihood of employability in this population, including supported and customized employment strategies. The chapter also provides information

on planning a career beyond a successful single job. The authors next provide strategies that may help businesses in hiring and supporting the employment of adults with ASD. A second major issue—*independent living*—is addressed in Chapter 12, by Myles and colleagues. They focus specifically on strategies that may help those identified with ASD described as high functioning. For successful independent living, many strategies have been shown to be effective, including modification of technology to promote aspects of such a life (e.g., financial and domestic issues). To help achieve these broad goals, the authors describe the Ziggurat Model as well as the Comprehensive Autism Planning System.

Chapter 13, by Markowitz, deals with an aspect of life that many families are reluctant to face: aging and its associated issues of estate planning and funding. The growth in the number of individuals with ASD has had a great impact on the number of adults needing services and lifelong oversight. The author reviews several life-sustaining factors, including appropriate medical care, the role of parents and guardians as advocates, and the transition from work to retirement. Markowitz provides a careful review of residential alternatives and what factors may influence their selection. Finally, there is a review of issues related to funding for services and support. The last chapter, Chapter 14, by Frantz and Zellis, provides invaluable information regarding the legal rights and challenges associated with adults with ASD. They review cultural misrepresentations of individuals with ASD and how these may influence opportunities and reactions, including by police personnel. They review several cases of adults with ASD whose behaviors led to involvement with our judicial system. The chapter ends with suggestions on what a family may consider when seeking legal advice and representation.

We hope the reader will find these chapters both informative and provocative. There are some clear suggestions and guidance based on research. However, the reality is that solid research on the well-being of adults with ASD is in its infancy. We hope that each chapter will provoke discussion, debate, and thoughtful discourse about how to best help those with ASD lead productive and satisfying lives. We also hope that these discussions will lead to a new area of research dedicated to providing professionals and caregivers with more evidence-based guidance to help make crucial choices regarding strategies and goals for adolescents and adults with ASD.

REFERENCES



- Baio, J. (2012). Prevalence of autism spectrum disorders—autism and development disabilities monitoring network, 14 sites, United States, 2008. *MMWR Surveillance Summaries*, 61(SS03), 1–19.

- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., et al. (2009). Prevalence of autism-spectrum conditions: UK school-based population studies. *British Journal of Psychiatry*, 194(6), 500–509.
- Gal, G., Abiri, L., Reichenberg, A., Gabis, L., & Gross, R. (2012). Time trends in reported autism spectrum disorders in Israel, 1986–2005. *Journal of Autism and Developmental Disorders*, 42(3), 428–431.
- Kim, Y., Leventhal, B. L., Koh, Y., Fombonne, E., Laska, E., Lim, E., et al. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168(9), 904–912.

Copyright © 2014 The Guilford Press