

Preface

Asperger Syndrome or Autism?

This is a book about Asperger Syndrome (AS). I happen to have a personal interest in this topic as our adopted son, Bernie, was given this diagnosis at age 14. Bern's arrival at 3 weeks of age in the Gullotta household was greeted with joy by mom, dad (me), and our golden retriever who immediately took up residence under his crib. Dickens or Nanny, if you prefer, insured that Bernie's slightest need was addressed promptly by either mom or dad and preferably both. This, she accomplished by entering our bedroom and emitting an ever-so-low soft short yelp. If we chose to ignore this signal, she would place her front paws on one of us and with copious doggie kisses disrupt any thoughts whatsoever of staying in bed. With such attention one might assume that Bern would quickly fall into a pattern, but this was not the case. He was a fussy baby who despite our every effort just seemed uncomfortable with his surroundings. By age two, we were on a search that proved fruitless at that time to explain a behavioral pattern that did not respond to a typical reinforcement schedule. Bern seemed oblivious to discipline that other children responded to when applied fairly and consistently. Bern seemed unable to learn from his mistakes – repeating the same social and behavioral errors again, again, and again.

By age five, the first of several diagnoses was attached to our son. In keeping with the medical principle of do as little (stigmatizing) harm as possible, our family journey with DSM IV-R began with ADHD. As the years went by, it grew with the addition of learning disorders, depression, and then bipolar disorder at 12 years of age. I will never forget the utter sense of hopelessness and helplessness I experienced with this last diagnosis. I can still remember, as if it were yesterday, walking the aisles of the Barnes & Noble bookstore in Washington, DC, searching for alternative medicinal treatments, so desperate had my search for help for him become. And then at age 14, after our family had been knocked off its unstable perch with my heart attack, Bern was diagnosed with Asperger Syndrome. Mind you as with so

many other young people with this disorder, other issues were still alive and well in making his life difficult to live, but the overall picture moved from utter fuzziness into almost understandability.

It is amazing how labeling a pattern of behavior correctly can bring about a response that actually achieves positive change. It is amazing how understanding a behavior like Asperger Syndrome can relieve parents of the enormous guilt that their inability to parent successfully is due solely to flaws (previously unknown) in their personalities and behavioral patterns. It is amazing how such utterly bad news can be a new beginning for a young person who has experienced in the totality of his life so few moments of positive community recognition.

Perhaps because our family is walking this journey, we find discussions within the APA DSM V study group regarding Asperger Syndrome disconcerting. In an attempt to simplify the confusion surrounding autism, Pervasive Developmental Disorder (PDD), Asperger's, etc., the concept of "one size fits all" has been introduced. This is a mistake. This book is in reaction to that error. Still, many of our colleagues will react to a book title such as *Asperger Syndrome: A Guide for Professionals and Families* appearing in the second decade of the twenty-first century with a remark like, "Where have these editors been. Aren't they aware that the new DSM V will consign this category to the diagnostic waste heap?"

Yes, we are aware of the desires of many within the psychiatric community to rid themselves of this troublesome diagnosis, and we believe that they are wrong. The individual who presents the symptoms that Hans Asperger first described in 1944 is different than the individual that Leo Kanner identified in 1943.

No one can deny that Asperger's description of young people displaying a unique set of symptoms that would ultimately come to bear his name has resulted in an expansion of basic research, practice innovation, and program that has benefited the individual with this diagnosis and those, too, with the diagnosis of autism. The parents of children with an AS diagnosis have expressed appropriate concern that services and medical coverage for their children might be curtailed if this change to DSM V should go forward. They have also questioned whether this repackaging effort of "one size fits all" will relieve school systems from the present difficulties they have in designing an appropriate educational program for these young people. Parents fear justifiably that the remarks all too often expressed at Individualized Education Programs (IEP) meetings that, "We have an appropriate educational experience for children with autism," will be applied to their child no matter how inappropriate the reality of that comment might be. Frankly, those of us with children who experience this disorder are not interested in making it easier to pigeon-hole these youth, these adolescents, and these adults. We have had firsthand experience with their difficult childhood, their painful adolescence, and their all too often disappointing adulthoods filled, as they often are, with unemployment and failed personal relationships. We are not interested in making it any easier for a child delivery system or any other social service system to inadequately serve their educational, mental health, and social services needs.

Neither Ray nor I will deny that the young person with an AS diagnosis may share certain characteristics with the young person with an autism diagnosis.

However, it is not the shared characteristics that matter but where these young people often differ that matters. This volume is devoted to those differences and where assistance can be offered to build their educational, vocational, and social skills to enable these individuals to experience the success that so often eludes them.

The chapters in this volume can be clustered into three general groupings, with the first two offering the reader an introduction to the subject matter. In the first chapter, Metz provides a primer to the uninitiated and draws a distinction between Asperger Syndrome and autism. In drawing that distinction, she acknowledges the occasional overlapping of behaviors that occur between the high-functioning individual with autism and the individual diagnosed with AS. Aspy and Grossman in chapter 2, “Assessment and Diagnosis of Asperger Syndrome” provide the educator and clinician with a useful approach to the identification of individuals with the AS diagnosis. They note that many mental health clinicians educated before the 1980s have little, if any, grasp of the AS diagnosis. Further they point out that while the study group working on DSM V appears ready to merge the autism and AS diagnostic classifications, the World Health Organization with its diagnostic manual, ICD-11, intends to maintain the distinction between the two disorders.

From definitions and characteristics to discerning those behaviors that suggest an individual should be diagnosed with AS, the second grouping of chapters addresses initiatives to improve the quality of life of individuals with the AS diagnosis. For example, Sharp’s chapter examines those behavioral and psychopharmacological interventions that may be helpful for individuals diagnosed with AS. In her review, Sharp compares specific treatments against the current outcome literature and then provides a comprehensive overview of the use of medication and its results on treating this disorder. In chapter 4, “Early Intervention for Children/Youth with Asperger Syndrome”, Baker-Ericzén continues this theme of action in examining early intervention strategies with this population. After reviewing the major theoretical explanations for AS, this chapter then focuses on encouraging cognitive flexibility and metacognition skill building in this population. The theme of building social skills continues with the chapter by Brenda Smith Myles and The Ziggurat Group. It offers the reader an extensive evidence-based overview of progress in this area since the publication of the first edition of this book.

The third grouping of chapters in this volume looks at educational efforts to appropriately and successfully equip these young people with the academic and social skills to live full and productive lives. The reader will find in chapters 6 and 7, “Evaluating Evidence-Based Instruction for Children with Asperger Syndrome” and “Comprehensive Education-Based Mental Health Services for Students Diagnosed on the Autism Spectrum”, written by DuCharme and his colleagues, a systematic evidence-driven approach to addressing the needs of this population that has been tested and refined at “The Learning Clinic” for the past two decades. DuCharme’s work in this area deserves replication.

The final chapter in this volume, by Jennifer Blackwell, is written by a parent. Its advice is gained from the long and often tearful journey all parents make on behalf of their children. I suspect that parents reading this chapter will identify with many of Jennifer’s experiences and observations. In a sense, this chapter is confirming

that we are not alone when we feel most alone. In another sense, it is a clear message to the helping and school communities offering insights into ways in which they can improve their efforts to help and educate individuals with an AS diagnosis.

I conclude this Preface having not answered the question poised in the title. Is the World Health Organization correct in maintaining the Asperger Syndrome diagnosis or is the study group working on DSM V correct? Will simplifying this diagnostic category improve services or will they provide an excuse to educators and health insurers to deny services? This volume raises questions but is admittedly short on conclusive answers. But this I do know. From that time when the medical and educational world was confronted with the words “Asperger Syndrome,” more work in basic research, education, medicine, and behavioral health has been undertaken than ever before to address this diagnosis *and* autism. As a parent of an adult with an AS diagnosis and a health professional keenly aware of the politics of health care, I am not ready to trust the system.

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Asperger Syndrome

A Guide for Professionals and Families

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