The Parent’s Guide to College for Students on the Autism Spectrum

Jane Thierfeld Brown, EdD,
Lorraine E. Wolf, PhD,
Lisa King, MEd,
and G. Ruth Kukiela Bork, MEd
Acknowledgments

Our sincere thanks to the hundreds of parents who have shared their children, their stories, and their challenges with us.

Our sincere thanks to all of the students we have worked with over the years. You have taught us and guided us in ways we never even imagined.

Our sincere thanks to all the educators who return day after day to help their students move onward and upward.

Our sincere thanks to the clinicians who work with all our children on the autism spectrum.

And, finally, to our families, you are the inspiration for our work, the spark for our passion, and the love that fuels our motivation. Thank you all.

Jane Thierfeld Brown
Lorraine Wolf
Lisa King
Ruth Bork
# Table of Contents

Introduction ........................................................................................................... 1

Chapter 1 Where Have You Been and Where Are You Going? ........ 7

Chapter 2 Finding The Right College ................................................................. 27

Chapter 3 Applying for Admission ................................................................. 51

Chapter 4 Getting Your Student to Campus .................................................... 63

Chapter 5 Laws Families Need to Know ......................................................... 79

Chapter 6 Who’s Who on Campus ................................................................. 99

Chapter 7 The Incoming Freshman ................................................................. 109

Chapter 8 Working With Disability Services .................................................. 121

Chapter 9 Academic Issues Your Student May Encounter ......................... 129

Chapter 10 Housing and Residential Life ...................................................... 141

Chapter 11 Student Health – Physical and Mental ......................................... 163

Chapter 12 Social and Extracurricular Life .................................................... 179

Chapter 13 Life after College ........................................................................... 187

Conclusion ........................................................................................................... 199

References .......................................................................................................... 203

Recommended Readings .................................................................................... 205
Introduction

College students on the autism spectrum are becoming increasingly common on U.S. campuses. In the late 1990s when the authors presented at a national conference of disability services providers, most of the attendees had never heard of Asperger Syndrome or other autism spectrum disorders. And those who did have experience with this population were mystified and concerned about how to best provide services, support success, and deal with the problems that inevitably arose during the college experience. The interest in our presentation was dramatic, with overflow seating on a Saturday afternoon. Yet, no one in attendance could have predicted the increase in numbers they were to see over the next decade. And none of us could have predicted that so many colleges and universities today not only know about autism spectrum disorders but are proactive in designing programs to support students.

Yet, despite such progress, school districts, families, educators, and health professionals across the country struggle daily with planning for life after high school, deciding whether college is appropriate, and if so, what kind of college, how far from home, and what kinds of services their student will need. No two students with autism spectrum disorders are alike. Each requires individual planning, goals, and resources to succeed. There is no one-size fits all. No college is appropriate for all students with autism spectrum disorders, and no student is a good fit for every college. The goodness-of-fit achieved and the planning that goes into the transition to college is often the single best predictor of student success. It is with this in mind that we bring our collective expertise and experience as university disability service providers, clinicians, educators, and parents to writing this book.*

* For ease of reading, throughout this book, instead of referring to students as “on the autism spectrum” or “with Asperger Syndrome,” we will refer to them simply as students with AS.
The Parent’s Guide to College for Students on the Autism Spectrum

We are disability services providers with over 100 years of combined experience. Some of us are also parents of kids on the autism spectrum. We all know how families feel from diagnosis to adulthood, from good years in school with great practitioners to difficult years. We have all faced, or are facing, transitions after school, transitions away from entitlement laws (see below). We have learned that regardless of the amount of planning and expert help, there will be tough times. However, we know that knowledge, awareness, and preparation assist with navigating rough seas ahead.

This volume concentrates on providing families, clinicians, teachers, and high school specialists information about the transition to college. We are aware that higher education is not appropriate for all students on the autism spectrum and that job training is an equal or better postsecondary option for some families (including one of the authors’ children). However, many students with AS benefit greatly from college, and we believe that students who can benefit from higher education should have that opportunity.

As parents, teachers, and clinicians, our commitment is to help ensure that students with AS become successful. As with more typical students, we hope they earn good grades, are comfortable in the classroom, and enjoy extracurricular activities, clubs, sports – all that college life entails. As we write this book, we realize that good intentions do not always lead to independence and success in adulthood. The success many students experience in high school is, in part, due to a carefully planned curriculum, complete with a team of supports – not the least of which is the parent. However, this level of support is rarely available on most college campuses. In order to succeed in college, students must be able to navigate a complex social world and academic rigor simultaneously. For some students on the spectrum this is attainable; others require assistance.
It has been said that parents interpret their child with AS to the world and interpret the world to their child. Once a child is launched from home into college, who will act as the interpreter? Over the last decade, we have seen postsecondary programs being developed all over the world. All such programs struggle to develop means to interpret college to students. Programs continue to expand each year. We do not list individual programs in this book, as that information would be outdated before the book is even published. Rather, we list some programs on our website, www.CollegeAutismSpectrum.com. Each family must investigate, call, visit, and investigate again prior to selecting an individual postsecondary option.

This is an exciting time for people with AS. Services and programs are constantly evolving, yet in many areas of the country, services only exist up to age 18. As with all of our children, those with AS spend up to four times as long as adults as they do as kids, and as a society, we must provide preparation for adulthood for students with AS. The alternative is to leave growing numbers of our population to a life of needing care rather than being able to care for themselves and living satisfying adult lives, making useful contributions to society. As postsecondary educators, we believe that college may provide the best launching pad for students who are able to use it.

As you read this book, we ask that you keep an open mind about your student and what he or she may or may not accomplish. Not
everyone must graduate from college, and some students who do graduate from college are not successful adults. Some students need one or two years after high school before starting college; others need to go part time while working and practicing life skills. There is no one way to be successful, no matter how many friends and neighbors believe there may be. Sometimes our students are more successful than we anticipate, so keep your mind open to that possibility as well. More than anything, be realistic about your hopes and dreams and ask the student to do the same. Is your student holding himself back or are you? Is the student being realistic enough or does she need a trusted adult to explain things? An open mind will make this book most useful to you and to your student.

Significant changes to diagnostic practice and standard nomenclature are in the works that will have a large impact on how we refer to a range of diagnoses currently falling under the “autism” umbrella. These changes will affect familiar terminology such that diagnostic distinctions between types of pervasive developmental disorders will no longer be made, while some diagnostic labels may vanish altogether. With this change, the diagnostic term of choice will change to “autism spectrum disorders.”

Philosophically, we believe in the continuum of the autism spectrum, regardless of the specific diagnosis assigned. We believe that postsecondary options similarly are tailored to the individual, not to the diagnosis. For that reason, we feel that interventions de-
signed for students with “Asperger Syndrome” could be just as effective for students with high-functioning autism, pervasive developmental disorders—not otherwise specified (PDD-NOS), or nonverbal learning disabilities (NVLD). In keeping with this philosophy, we will refer to “students with AS” or “students on the spectrum” throughout the book.

In addition, while the prevalence of AS is greater in males than in females, we will alternate pronouns through the book in recognition of the many girls and young women with AS we have encountered. We are optimistic that whichever direction diagnostic processes take, students can and will thrive in college to the extent that families, students, educators, and college administrators are aware and open to change.

What You Can Expect
This book is arranged in the order your family will go through the college process from looking at where you have been and where your student is going, to how to look for a college, the admissions process, etc. Each chapter begins with an overview and a vignette of a student and where he or she is in the college process. The vignettes are about different students to make the examples as comprehensive as possible in hopes that readers will find issues from their own family in some of them.

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This book, written by experienced college disability directors, is the authoritative guide to the subject. Dr. Lorraine Wolf and Dr. Jane Thierfeld Brown lead AANE’s ‘Preparing for College’ workshops, and Dr. Thierfeld Brown offers college consultations to individual teens and their parents. Learn More and Purchase. Related Topics According to College Autism Spectrum, 15 colleges have programs for students on the autism spectrum, while many others have trained staff who can work with such students. The email in question intended to start a guide about which girls are most willing to have sex, plus which fraternity brothers are getting the most action. The misogynistic letter that went viral referred to women as “targets” and their vaginas as “pies,” and stated that they’re not “actual people.” Gross! So who wrote it? "We learned the email did not originate at USC. The student who sent it is not a member of the USC chapter of Kappa Sigma and received it from a friend at another university on the East Coast," said Michael L. Jackson, vice president. For parents whose adolescent with autism spectrum disorders is considering college, this practical book is an invaluable guide to evaluating college readiness, strengthening key skills, identifying the right match, ensuring the smoothest possible transition, and creating a safety net to maximize the chances of a successful college experience. She is a frequent presenter and trainer, locally and nationally on topics related to best practices for working with students on the spectrum in higher education settings. G.Ruth Kukiela Bork, M.Ed., is dean and director of the Disability Resource Center, Northeastern University. Dean Bork’s professional involvement in disability affairs and advocacy spans 34 years. She is a founding member of the Association on Higher Education and Disability (AHEAD).