

# Social and Emotional Support for Autistic Students on Campus



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By

Ken Gobbo

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## PREFACE

This book began as a course offered by The Landmark College Institute for Research and Training (LCIRT). LCIRT aims to conduct innovative research and develop strategies and practices that will improve learning outcomes for students. Their certificate program in Learning Differences and Neurodiversity, an online postbaccalaureate professional program, includes a specialization in Autism. The contents of one of their core courses titled “Social and Emotional Support for Autistic Students on Campus” provided a framework for the central ideas discussed in this book. The course and this book feature the research and theoretical underpinnings that support strategies and practices used by Landmark College’s staff and faculty to support autistic college students as they face the social and emotional challenges that may hinder progress toward their academic goals. The course and this book present the best of many years of work by the college’s student development staff and faculty, who are dedicated to the academic success of students who learn differently. The most important result of this work has been the graduation of many autistic students who have since embarked on successful professional careers.

Researchers began actively tracking the increasing rates of autism around the year 2000. Not surprisingly, ten or twelve years later, as those increasing numbers of autistic young people graduated high school, they applied to and were accepted into community colleges, four-year colleges, and universities in growing numbers. Landmark College, being an institution dedicated to teaching students who learn differently, naturally experienced a growth in the numbers of autistic students among those it served. Its faculty and staff intentionally implemented a teaching and learning environment suited to their needs and designed programs that facilitated the students’ academic and social development.

This book is part of an effort to extend that work and offer information, ideas, and techniques to educators, family members, students, and anyone interested in supporting the academic progress of autistic college and university students. It draws on the research and work of many who have dedicated themselves to the growing understanding of how autistic students experience and interact with their campus environments. The book also intends to present a view of autism through the lens of neurodiversity, with



an understanding of a growing neurodivergent culture. Neurodiversity, which offers a positive view of the multitude of naturally occurring variations in the human nervous system, is also an identity and a social justice movement, which will be discussed in depth later in this book.

As an author of a book on the topic of autism, it is important to explain that because I am not an autistic person, I can never have a full understanding of what it is like to be autistic. My work presented in this book is based on research, reading of the available literature, my years of experience working alongside autistic college students in classrooms as an academic advisor, and living and learning with them on study abroad programs around the world.

K.G.  
Putney, VT  
November, 2022

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# INTRODUCTION

Since the 1700s, there have been scientific accounts of individuals who communicate differently. The use of the term “autistic” to refer to the narrowing of relationships was originally used more than one hundred years ago, early in the history of psychology. In the mid-twentieth century, psychologists began to refer to children who related differently to the outside world, some of whom had “islets of ability,” as autistic. As we enter the third decade of the twenty-first century, the diagnosis of autism spectrum disorder (ASD) is assigned at an ever-increasing rate. Estimates by the Centers for Disease Control and Prevention (CDC) for the prevalence of autism in the United States in 2010 indicated that 1 in 68 had autism. By 2018, the estimate had risen to 1 in 59 (Baio et al. 2018), and by 2020 the rate had risen to 1 in 54 (Maenner et al. 2020). By the end of the year 2021, an estimate by the CDC indicated that the prevalence rate for autism among children was 1 in 44, or 2.3 percent (Maenner et al. 2021). Autistic individuals now make up a substantial portion of the population in the United States. As the size of the population of autistic people grows, so too does the understanding of this neurologically-based difference, and the increasing possibility of harnessing the skills and talents of those in this group.

For more than half a century, the medical model which views autism as a disorder has prevailed. Over the past decade and a half, the neurodiversity movement has provided the impetus for an ongoing shift away from viewing autism as a disorder in need of a cure, towards a view that recognizes both the positive elements of the condition and its role in identity formation, as well as the frustrations and social struggles experienced by individuals with autism. In recognition of one of the most basic principles of the neurodiversity movement - that is, the opinions of neurodivergent individuals should be included in the study of processes that shape their lives, including the establishment of research agendas and policy development - neurodivergent individuals have been involved in the planning of the course this book is based on. They have also been invited to react to and comment on the content of the book itself, and they have offered advice, shared their experiences, and helped to shape the final version of the book. The book will also offer brief summaries of the lives of a handful of

autistic exemplars who have made significant contributions to both neurodivergent and mainstream culture.

There is ample evidence that many autistic individuals are more than intellectually capable of completing undergraduate and graduate courses. The numbers of autistic students enrolled in United States and United Kingdom institutions of post-secondary education range between 0.7 and 2 percent and are steadily increasing (Gurbuz, Manly, and Riby 2019). Current information on educational outcomes for autistic students is mixed when comparing their graduation rates to the general neurotypical population. The National Autistic Indicators Report notes a graduation rate of 20 percent for autistic students as compared to a national graduation rate in the United States of 60 percent for undergraduates (Roux et al. 2016). Research by Kathleen Viesel (2021) indicates that autistic students enter colleges and universities with good academic abilities, and the first-year persistence rates are high. Also, recent research indicates that many autistic students flourish in a higher education setting (Irvine and MacLeod 2022) in spite of the continued work needed to provide autistic-friendly spaces. Still, they often face struggles with socialization, sensory concerns, and daily living skills that can have a negative effect on academic outcomes. During these challenging times when society becomes ever increasingly reliant on technology in every sector of life, the creativity, skills, and talents of the autistic population have become more needed than ever. Finding ways to support students as they navigate the social obstacles that can slow academic progress will only benefit our society in the long run.

The primary goal of this book is to highlight those social and emotional issues faced by autistic students in post-secondary and secondary educational settings. It will provide an overview and examination of autism from traditional medical and more recent neurodiversity points of view. It will also explore developmental, social, and emotional challenges encountered by many autistic adolescents and young adults. Specific topics include theories of autism, transitioning to adulthood, masking and camouflage, issues related to gender and sexuality, issues specific to girls and young women, living in a community, conflict resolution, controversies, and future directions. My sincere hope is that the information presented here will be of help to professionals who work to support autistic students as they reach for their goals. I feel that families of autistic students, as well as any individuals who are interested in better understanding this growing population, will find it helpful. Finally, of course, it will be of interest to members of the neurodiversity community, and anyone working to further their understanding of this complex condition called autism.

## References

- Baio, Jon, Lisa Wiggins, Deborah L. Christen, Matthew J. Maenner, Julie Daniels, Zachary Warren, Margaret Kurzius- Spencer, et al., 2014 “Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States.” *MMWR Surveillance Summary* 67 (6): 1–23. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5919599/>
- Gurbuz, Emine., Mary Hanley, and Deborah M. Riby. 2019. “University Students with Autism: The Social and Academic Experiences of University in the UK.” *Journal of Autism Developmental Disorders* 49: 617–631. <https://doi.org/10.1007/s10803-018-3741-4>
- Irvine, Brian and Andrea MacLeod. 2022. “What are the challenges and successes reported by autistic students at university?: a literature review.” *GAP* 23 (1). (PDF) What are the challenges and successes reported by autistic students at university?: a literature review (researchgate.net)
- Maenner, Matthew J., Kelly A. Shaw, Amanda V. Bakian, Debora A Bilder, Maureen Durkin, Amy Esler, Sarah Fournier, Libby Hallas, Jennifer Hall-Lande, Allison Hudson, et al., 2021. Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years – Autism and Developmental Monitoring Network, 11 Sites, Unites States, 2018. *Surveillance Summaries* 70 (11): 1-8. <https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm>
- Maenner, Matthew J., Kelly A. Shaw, Jon Biao, Anita Washington, Mary Patrick, Monica DiRienzo, Deborah L. Christiansen, Lisa D. Wiggins, Sydney Pettygrove, Jennifer G. Williams, et al., 2020a.” Prevalence of Autism Spectrum disorder among Children aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites United States.” *MMWR Surveillance Summary* 2020 69 (4): 1-12. DOI: 10.15585/mmwr.ss6904a1
- Roux, Anne M., Paul Shattuck, Jessica Rast, Julianna Rava, and Kristi Anderson. 2015. “National Autism Indicators Report: Transition into Young adulthood. Philadelphia PA: Life Course Outcomes Research Program Area.” A.J. Drexel Autism Institute, Drexel University. <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/>

Viezel Kathleen D., Benjamin Freer, and Chelsea D. Morgan. 2021.  
“Adaptive Behavior of College Students with Autism.” *Focus on Autism  
and Other Developmental Disabilities* 37 (1): 56-65. DOI:  
10.1177/10883576211056291

# CHAPTER 1

## WHAT IS AUTISM?

An important starting point in any discussion about autism is the recognition that it can manifest itself in a variety of different ways. For this reason, it is critical to start with a general overview of the condition and to discuss some working definitions. This chapter will provide a general description from neurodiversity and medical points of view, and review some basics on prevalence, risk, and related disorders. It will also examine the context of this spectrum disorder.

Autism is a complex condition or perhaps even a group of conditions. It is a neurodevelopmental condition that results in different ways of communication, repetitive patterns of behavior, and restricted interests. It is referred to as a spectrum disorder because it includes a wide range of levels of severity and features. Some autistics can perform the required actions necessary for daily adult independent living while others need support. It lasts for a lifetime. Appropriate support can help autistic individuals to improve their ability to function in day-to-day situations.

Every autistic person is likely to describe autism a little differently. The Autism Self Advocacy Network (ASAN) describes autism as a developmental disability that affects how one sees the world. It affects people of all colors, social and economic statuses, sexual orientations, and genders. The communities that people belong to shape their experience of autism. People who are autistic think differently, communicate differently, and socialize differently (ASAN 2022). They may need assistance with the tasks of daily living.

Consider the American Psychiatric Association's point of view. It is a medical approach to autism outlined in their *Diagnostic and Statistical Manual* (American Psychiatric Association 2022), commonly referred to as the *DSM-5-TR*. This edition, published in 2022, serves as the standard reference guide to "disorders" used by the medical community in the United States. It describes autism spectrum disorder as the experience of persistent deficits in the ability to initiate and sustain social communication and

interaction, as well as different types of restrictive repetitive behaviors. Symptoms include deficits in social emotional reciprocity, deficits in nonverbal communicative behaviors including eye contact, use of gestures, and lack of facial expressions, deficits in developing, maintaining, and understanding relationships, stereotyped or repetitive motor movements, insistence on sameness, highly restricted, fixated interests that are abnormal in intensity or focus, and hypo or hyper reactivity to sensory input. Symptoms must be present in the early developmental period and they must cause clinically significant impairment to functioning. This clearly describes a deficit model- it focuses on restrictive, repetitive patterns of behavior or interests that are present in early childhood. It indicates that symptoms limit or impair daily functioning and it states that manifestations vary greatly. The *DSM-5- TR* also provides for the rating of three levels of severity for social communication and restrictive repetitive behaviors: level one requiring support, level two requiring substantial support, and level three requiring very substantial support. This description has gone through changes over time. Four previously separate categories of autism have been consolidated into one umbrella diagnosis of autism spectrum disorder in the most recent edition of the *DSM*. Asperger's Syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified have all been incorporated into the autism spectrum disorder diagnosis. While diagnosticians use the *DSM* in the United States, a large part of the world uses the World Health Organization's classification systems known as the *ICD-10* and the *ICD -11* (2020). The acronym ICD stands for International Classification of Diseases. It provides a set of global health standard guidelines for diagnosis and is currently moving into its eleventh edition. The *ICD – 11*, published in 2019, has been in use since early 2022. It includes all different kinds of disorders and diseases; physical, neurological, and behavioral.

In considering autism, the *ICD 10*-divides the condition into three subtypes: childhood autism, Asperger's syndrome, and pervasive developmental disorder. In a way similar to the changes that were made during the transition from the *DSM-IV* to the *DSM-5*, the *ICD-11* incorporates childhood autism and Asperger's syndrome into a single category marked by social communication deficits and restrictive inflexible repetitive patterns of behavior, interests or activities. It mirrors the changes previously expressed in the shift from the *DSM IV* to the *DSM 5*. The *DSM 5* previously relinquished the three subtypes and moved to the idea of a continuous spectrum reflecting the variability of symptoms and how they are expressed. The general descriptions of symptoms related to social communication and restrictive repetitive behaviors are similar in both diagnostic systems.



Differential diagnosis is a process by which one condition is distinguished from other similar conditions or disorders. Some conditions that share symptoms with autism are selective mutism, language disorder, social pragmatic disorder, and stereotypic movement disorder. For example, if someone exhibited stereotypic, repetitive movements, but not social difficulties, they might receive a diagnosis of stereotypic motor disorder rather than autism spectrum disorder.

## **Prevalence**

With the world's recent experience with COVID, the general public has become more familiar with the science of epidemiology. Prevalence rates for autism are tracked by The Centers for Disease Control and Prevention. They regularly gather and disseminate information on health trends. Prevalence is the proportion of a population experiencing a condition at a given point in time, usually expressed as a percentage of a given population. According to the Centers for Disease Control, 2020 estimate, one in 54 or 1.5 percent of children in the United States were diagnosed with autism spectrum disorder (Maenner et al. 2020). A later estimate reported at the end of 2021 indicated that one in 44 or nearly 2 percent. in the United States meet the diagnostic criteria for autism. The condition is 4.2 times more prevalent in boys than in girls. In 2000 and 2002 about half of those diagnosed with autism were also diagnosed as having an intellectual disability. In the most recent 2021 report that portion of individuals is lower, approximately one third (Maenner et al. 2021).

In the 1960s and 1970s in Europe and the United States, the reported prevalence estimates were in the range of six to seven cases per 1,000 children. By 2002 estimates, prevalence rates for adults with autism spectrum disorder ranged from a low of 1.9 percent in the state of Louisiana to a high of 2.4 percent in Massachusetts. States with the greatest number of adults living with ASD included California, Texas, New York, and Florida. Variations are likely attributed to availability of diagnostic services.

## **Increased Likelihood**

In this section “increased likelihood” refers to factors that increase the incidence of a condition. These factors for autism include being male as boys are four times as likely to be diagnosed as girls are. Advanced parental age, low birth weight, complex and premature birth may also contribute to the increased likelihood of ASD. Having a sibling with ASD and having

certain genetic conditions including Rett Syndrome also increase risk. Heritability studies range 30 percent to above 90 percent based on twin concordance studies. In these studies epidemiologists look at identical twins who are genetically the same and predict the chances of a second twin having a condition if the first twin experiences it. Research indicates that autism is polygenic in nature with a large number of genes involved. If you consider the number of genes involved in speech, gesture, facial expression, body language and other factors affected by autism the number of genes involved in these must be VERY large. Recent genetic research has focused on regions in chromosomes 16 (Weiss 2019). Genetic conditions including Fragile X Syndrome, may increase risk. While advances in the field of genetics are beginning to inform us about possible relationships between genetic variants and autism, there is still a long way to go in understanding the relationship between genes and environment and the occurrence of autism.

The research has indicated for some time that there are no reliable scientific studies that indicate a connection between autism and vaccination.

## **A Spectrum Disorder**

The term “spectrum” in “autism spectrum disorder” refers to the wide range of symptoms and severity. Individuals with ASD are likely to have a unique pattern of behavior. The levels of severity also vary in range often referred to as low functioning to high functioning (Mayo Clinic 2019; APA 2022).

In readings and discussions of autism one frequently encounters reference to high functioning and low functioning levels of the condition. These two descriptors, high and low, generally refer to autism without and with intellectual disability. This binary approach to understanding the functioning of autistic people has proved to be a less than useful way to categorize individuals. While some claim that intelligence quotient is the best predictor of symptom severity, experience and research has shown that it is not the most accurate measure of ability to adapt to the environment (Alvares et al. 2020; Minneshaw and Williams 2008). It is also important to keep in mind that severity of symptoms can decrease over time. Early childhood predictions of levels of social functioning can become inaccurate (Waizbard-Bartov et al. 2020; Fine et al. 2013) with girls tending to show greater reduction in autistic features over time (UC Davis 2020).

C.L. Lynch (2019), an author who describes herself as a “socially awkward autistic” accurately states that autism is not a set of defined symptoms that

collectively worsen as one moves “across” or “up and down” the spectrum. In fact, one of the distinguishing features of autism is what the *DSM* calls an “uneven profile of abilities.” Every autistic person presents slightly differently. As mentioned in the description of the condition, autistic individuals usually have issues with several areas including social functioning, sensory processing, highly focused interests, and other areas. Many view autism as a collection of related neurological conditions that are intertwined. It is not a two directional spectrum. Lynch describes the multitude of variable combinations involving pragmatics, social awareness, sensory processing, repetitive behaviors, and neuro-motor differences in a variety of combinations.

## Twice Exceptional

Recently the view of “giftedness” has broadened. It has moved away from Lewis Terman’s century old concept that only included those with very high Stanford Binet I.Q. scores to a broader, more diverse, interdisciplinary view that includes cognitive diversity (Sternberg and Ambrose, 2021). This new view and definition of giftedness now includes more members of the neurodivergent community, particularly autistic students who have a great deal to offer when confronting and generating solutions to complex twenty-first century problems.

The term twice exceptional, by definition includes students who are members of the neurodivergent communities and have a gift or talent of some kind that provides potential for high achievement in an area of human productivity. Because of their high intelligence, many autistic students, are academically qualified and more than academically able to succeed in post-secondary settings. Joseph Renzulli (2011) presents a useful definition of “giftedness” in his discussion of the intersection of above average ability, creativity, and commitment to task. Autistic students with high cognitive abilities, a tendency toward “out of the box” thinking, and a kind of perseverance that might be harnessed, may meet all three Renzulli’s qualifications in his definition of “giftedness.”

Qualitative case study research indicates that experience which supports postsecondary academic success emphasize the importance of nurturing the qualities described above. Reviews of several case studies support the importance of offering gifted autistic middle and high school students opportunities to develop their chosen and often deep interests. Extracurricular activities like science and engineering clubs that are project oriented, debate clubs, and improv groups all allow for the development and expression of

student interests. They also allow students to develop and practice social pragmatic skills they will need later in their educations to support their academic skills. Short-term residential opportunities like summer camps also provide important social experiences for students (Reis, Gelbar and Madeus, 2021, Gelbar, Cascio, Madaus, and Reis. 2021, Chen et al. 2021). While participation in “residential” programs may be particularly challenging for autistic students (and their parents) they begin to provide opportunity for students to navigate social challenges in lower stakes situations than a semester long college or university residential program would offer. Short-term “camp” situations also gradually build self-confidence and reduce anxiety over anticipated changes of being away from home.

## **Biology**

There is an incredible heterogeneity among autistic people. A recurring theme in this book will be the complexity of autism and how variable the presentation of the condition can be. Autism is a neurologically based difference, and it is important for autistic individuals, their families, and all who support them to understand this when individuals face the obstacles that are likely to come between them and their educational goals. Considering the incredible complexity of the human nervous system, and the many possible variations in the behavior they produce, it is no wonder that the search for the biological underpinnings of the condition is daunting and complicated. Over the past fifty years scientists who explore the multitude of facets of the autistic nervous system have made slow progress in understanding the brain differences related to autism (Ecker, Spooren and Murphy 2012; State and Stetson 2012). While there are no reliable biomarkers for autism as of this writing, should consistent markers emerge from the many candidates currently under consideration, ethical issues related to the most appropriate use of these markers will need to be addressed. Translational work related to helping individuals and supporting the needs for the growing autistic population will always need to be in the forefront of the research agenda.

Adelphi University Professor, Stephen Shore points out, “If you have met one person with autism, you have met one person with autism.” This famous and often used quotation about autism, makes the point that there is an incredible range of severity and heterogeneity among autistic people. Autistic experience is more complex than a two-dimensional scale, and experience can change in variety and intensity from day to day as well as

from person to person. A person is not just functioning at the high end or low end of a spectrum; they are more or less sensitive to sensory stimulation day to day even hour to hour. As circumstances change abilities to respond can modulate during a school or workday. Abilities to concentrate, interact, focus, and process sensation and information all may shift over the course of a day. The result may be an unevenness in performance and resulting work. To sum it up, autism is a very complex condition.

## References

- Alvares, Gail A., Kiah Bebbington, Dominique Cleary, Kiah Evans, Emma J. Glasson, Murray T. Maybery, Sarah Pillar, Mirko Uljarević, Kandice Varcin, John Wray, Andrew J. Whitehouse. 2020. "The Misnomer of 'High Functioning Autism': Intelligence Is an Imprecise Predictor of Functional Abilities at Diagnosis." *Autism*. 24 (1): 221-232. DOI: 10.1177/1362361319852831.
- Ambrose, David. 2021. "Interdisciplinary Exploration Guiding Conceptions of Giftedness" In *Conceptions of Giftedness and Talent*. Edited by Robert J. Sternberg, and Don Ambrose. London: Palgrave, pp. 1-20.
- American Psychiatric Association. 2022. *Diagnostic and statistical manual of mental disorders*. Fifth edition. Arlington, VA: American Psychiatric Association.
- American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders: DSM-5*. Arlington, VA: American Psychiatric Association, <https://doi.org/10.1176/appi.books.9780890425596>
- Autism Self Advocacy Network. 2022. "About Autism." <https://autisticadvocacy.org/about-asan/about-autism/>
- Chen, Yu-Lun, Kavitha Murthi, Wendy Martin, Regan Vidiksis, Ariana Riccio, and Kristie Patten. 2021. "Experiences of Students, Teachers, and Parents Participating in an Inclusive, School-Based Informal Engineering Education Program." *Journal of Autism and Developmental Disorders*. Aug 19. DOI: 10.1007/s10803-021-05230-2. Epub ahead of print. PMID: 34410541.
- Ecker, C., Spooren, W. & Murphy, D. 2013. "Translational Approaches to the Biology of Autism: False Dawn or a New Era?" *Molecular Psychiatry* 18: 435–442. <https://doi.org/10.1038/mp.2012.102>
- Fein, Deborah, Marianne Barton, Ingrid-Marie Eigsti, Elizabeth Kelley, Letitia Naigles, Robert T. Schultz, Michael Stevens, Molly Helt, Alyssa Orinstein, Michael Rosenthal, Eva Troyb, and Katheryn Tyson, 2013. "Optimal Outcome in Individuals with a History of Autism." *Journal of*

- Child Psychology and Psychiatry, and Allied Disciplines* 54 (2): 195–205. <https://doi.org/10.1111/jcpp.12037>
- Gelbar Nicholas, Alexandra Cascio, Joseph Madaus, and Sally Reis. 2021. “A Systematic Review of the Research on Gifted Individuals With Autism Spectrum Disorder.” *Gifted Child Quarterly*. December 2021. DOI: 10.1177/00169862211061876
- Lime Connect Interview with Dr. Stephen Shore: “Autism Advocate and on the Spectrum.” 2018. International Board of Credentialing and Continuing Education Standards IBCCES. <https://ibcces.org/blog/2018/03/23/12748/>
- Lynch, C. L. 2019. ““Autism is a Spectrum” Doesn’t Mean What You Think.” *Neuroclastic*. <https://neuroclastic.com/its-a-spectrum-doesnt-mean-what-you-think/>
- Maenner, Matthew J., Kelly A. Shaw, Amanda V. Bakian, Debora A Bilder, Maureen Durkin, Amy Esler, Sarah Furnier, Libby Hallas, Jennifer Hall-Lande, Allison Hudson, et al., 2021. “Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years – Autism and Developmental Monitoring Network, 11 Sites, United States, 2018.” *Surveillance Summaries* 70 (11): 1-8. <https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm>
- Maenner, Matthew J., Kelly A. Shaw, Jon Biao, Anita Washington, Mary Patrick, Monica DiRienzo, Deborah L. Christiansen, Lisa D. Wiggins, Sydney Pettygrove, Jennifer G. Williams, et al., 2020. “Prevalence of Autism Spectrum disorder among Children aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016.” *MMWR Surveillance Summary* 2020 69 (4): 1-12. DOI: 10.15585/mmwr.ss6904a1
- Mayo Clinic. 2020. Autism Spectrum Disorders <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928>
- Minneshaw, Nancy J. and Diane L. Williams. 2008. “Brain Behavior Connections in Autism.” *Speaker’s Journal* 8 (5).
- Reis, Sally M., Nicholas W. Gelbar, and Joseph W. Madaus. 2021. “Understanding the Academic Success of Academically Talented College Students with Autism Spectrum Disorders.” *Journal of Autism and Developmental Disorders*, 1-14. <https://doi.org/10.1007/s10803-021-05290-4>
- Renzulli, Joseph S. “What Makes Giftedness?: Reexamining a Definition.” *Phi Delta Kappan* May, 2011. 92 (8): 81–88. <https://doi.org/10.1177/003172171109200821>.

- Shannon, Joyce Brennfleck, ed. 2011. *Autism and Pervasive Developmental Disorders Sourcebook: Basic Consumer Health Information About Autism Spectrum Disorders (ASD) Including Autistic Disorder, Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS): Along with Facts About Causes, Symptoms, Assessment, Interventions, Treatments, and Education, Tips for Family Members and Teachers on the Transition to Adulthood ... / Edited by Joyce Brennfleck Shannon*. Second edition. Detroit, MI: Omnigraphics.
- State, Matthew W., and Nenad Šestan. 2012. "Neuroscience. The emerging biology of autism spectrum disorders." *Science*. Sep 14; 337 (6100): 1301-3. DOI: 10.1126/science.1224989. PMID: 22984058; PMCID: PMC3657753
- Sternberg, Robert J., and David Ambrose, eds. 2021. *Conceptions of Giftedness and Talent*. Palgrave.
- University of California - Davis Health. "Autism severity can change substantially during early childhood: Study found gender differences in autism severity changes." *ScienceDaily*. [www.sciencedaily.com/releases/2020/05/200528160501.htm](http://www.sciencedaily.com/releases/2020/05/200528160501.htm) (accessed November 17, 2021).
- Waizbard-Bartov, Enat, Emilio Ferrer, Gregory S. Young, Brianna Heath, Sally Rogers, Christine Wu Nordahl, Marjorie Solomon, David G. Amaral. 2020. "Trajectories of Autism Symptom Severity Change During Early Childhood." *Journal of Autism and Developmental Disorders* 51: 227-242. DOI: 10.1007/s10803-020-04526-z
- Weiss, Lauren. 2019. "Research Update: Understanding Genetic Risk Factors for Autism." *One Mind*. Understanding Genetic Risk Factors for Autism: Dr. Lauren Weiss - One Mind
- World Health Organization (WHO). 2020. *International Statistical Classification of Diseases and Related Health Problems*. Eleventh edition. Genève, Switzerland: World Health Organization. <http://icd.who.int>

## CHAPTER 2

### HISTORY

The ways in which people view autism have changed a great deal over the past century. Points of view have shifted, as have the prevailing schools of thought throughout the history of psychology. This chapter provides a brief history of autism and the individuals who have shaped the changing views of this condition over the past century. There have always been individuals who interact with others differently. One of the most well-known people of this nature is referred to in the late eighteenth century “prescientific” case study by Jean-Marc Gaspard. German developmental psychologist and researcher Uta Frith (2003) writes about the case of Victor of Aveyron. Victor was a young boy found living in the woods of the French countryside at about the age of twelve. Although Victor could hear, he lacked speech and communication skills. Despite vigorous attempts at socialization, Victor made only rudimentary progress.

The first time we see the word autism used is by Swiss psychiatrist Eugen Bleuler in his portrayal of the symptoms of schizophrenia. In his 1911 description, he uses the term to refer to someone who withdraws into his own world. At the time, he was describing a kind of premature dementia, dementia praecox, which later became known as schizophrenia. In his discussion of the newly identified condition, he referred to the four A’s in describing symptomology: disturbances of Affect, Association, Ambivalence, and Autism. These referred to a loosening of associations, inability to make decisions, blunted affect, a preoccupation with the self and one’s own thoughts, and finally withdrawing into one’s own world.

In the then-Soviet Union, during the 1920s, Grunya Efimovna Sukhareva worked as a child psychiatrist. Her work, like that of Russian child psychologist Lev Vygotsky, was unknown in the West for a long time. Because of the Cold War, large numbers of scholars and other interested individuals in the “English-speaking world” were unable to access the work of Soviet psychologists in detail until late in the twentieth century. Sukhareva’s scholarly contributions were not translated and disseminated until the year 2000. In 1926, she published an account of a case study of a



child with symptoms similar to those of autism, as later described by both Kanner and Asperger (Manouilenko and Bejerot 2015).

Louise Despert, an American psychiatrist, published a study in 1938 which may have later inspired Leo Kanner, who is widely recognized for his early work on autism. In her work on childhood schizophrenia, Despert used the term “autistic thinking” and argued against the rarity of schizophrenia in childhood. The history of autism frequently highlights the work of Kanner and Asperger, but Sukhareva and Despert were both influential figures in this history who often do not get the credit that they deserve.

Leo Kanner, an Austrian-American, was one of the first child psychiatrists to practice in the United States. In 1943, he published a paper based on the study of eleven highly intelligent children who preferred to be alone and displayed an obsessive insistence on sameness. He called the condition “early infantile autism.”

Hans Asperger, an Austrian pediatrician, published an article in 1944 that described his work with a group of boys who had normal to high intelligence, but lacked social skills and had a restricted range of interests. Much later, in 1981, Lorna Wing coined the term “Asperger’s Syndrome” to describe a form of high functioning autism. This term was later used in the *DSM-IV* in 1994 (APA 1995). Recent research and writing have raised questions about Asperger’s involvement in eugenics under the Nazis during World War II. The goals of the Nazi regime included the development of a “pure” race and the killing of anyone deemed to be “genetically unfit.” Evidence suggests that Asperger may have been complicit in referring children to clinics he likely knew were “euthanasia centers” (Baron-Cohen 2018).

Asperger in Austria, and Kanner in the United States, worked with similar populations at about the same time. They are usually given credit for identifying what would become known as autism spectrum disorder. Little credit is given to the clinician who influenced both of them. George Frankl, a philosopher and child psychoanalyst at the Lazar Clinic supervised Hans Asperger, who had been appointed as head of a ward there (Muratori, Calderoni, and Bizzari 2021). Frankl worked closely with psychologist Annie Weiss, whom he eventually fell in love with and married. Asperger surely learned from both Frankl and Weiss while under Frankl’s supervision. During the Nazi regime, Jews like Frankl and Weiss had difficulty maintaining and advancing their professional careers. They even kept their romantic involvement quiet so as not to raise any suspicions that

might lead to dismissal. Still, Weiss lost her position at the clinic in 1934 and immigrated to New York, where she was appointed to a post at a Columbia University clinic. Frankl left the Lazar Clinic in 1939, likely feeling the growing pressure of Nazi overreach after the annexation of Austria to Germany. He travelled to New York, married Weiss, and found work, on Kanner's recommendation, as a child psychiatrist at Johns Hopkins in Baltimore (Robison 2017). More important than serving as a link between Asperger and Kanner, Frankl was the first to see autism as a concern related to affective (nonverbal) language (Muratori, Calderoni, and Bizzari 2021). He also viewed autism as being neurobiological in nature and covering a "spectrum of conditions" (Muratori, and Bizzari 2020).

During the period following World War II, psychoanalysis was still a very influential school of psychological thought in the United States and Europe. This point of view left a mark on how the general public viewed psychology and autism during the 1950s and early 1960s. The Freudian view of development emphasized the child's movement through specific stages while parents provided nurturing. Problems occurred if parents, usually mothers, were not nurturing enough, and the theory posited that a person then got stuck, or 'fixated', in the stage when parenting failed. While the more 'scientific' psychoanalytic theorists, such as Bowlby (1973) and Ainsworth (1978), contributed to the understanding of attachment and child development, some of the well-known psychoanalytic theorists' legacies are seen in a negative light by the autistic community today. Frances Tustin and Bruno Bettelheim are singled out for referring to autistic children as less than human, even applying the term 'monster' to these children (Waltz 2015, Waltz 2008, Bettelheim 1967, Tustin 1992). Tustin (1991) is known for her descriptions of the autistic child as one seeking sensation rather than contact with others. She places the cause of autism squarely at the feet of busy parents.

Bruno Bettelheim was probably one of the most well-known psychologists in the United States during the 1960s. He regularly appeared on television and his work was written about in the popular press frequently. His psychoanalytically based "Refrigerator Mother" theory, which has since been refuted, became well known both through media exposure and the publication of his book *The Empty Fortress* in 1967. His theory proposed that "poor parenting" caused autism, which was thought of as a type of schizophrenia. Bettelheim's theory gave little consideration to biology or genetics.

Dr. Lorna Wing, a British psychiatrist, is perhaps best known for popularizing the term “Asperger’s Syndrome.” In 1981, she applied this term to socially isolated children with precocious language skills and above average linguistic skills (Barahona- Correa and Philipe 2016; Wing 1981). The fourth edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual (DSM)* included the term. Wing was among the first to realize that autism could be considered dimensionally and that it could affect individuals of many different ages and intellectual levels. She also identified the “Triad of Impairments”, which includes social interaction, social communication, and imagination or rigidity and repetitive interests by autistic individuals. This was later referred to as “Wing’s Triad.” In 1995, she was appointed OBE (Order of the British Empire) for her work with The National Autistic Society.

Examining the changing view of autism over time reveals a variety of diagnostic descriptions of autism. The *DSM-II*, published in 1968, describes autistic withdrawn behavior as being associated with childhood schizophrenia (APA 1968). In the 1980 edition of the *DSM-III*, autism is differentiated from schizophrenia (APA 1980), and described as a pervasive developmental disorder. Revised again in 1980, the *DSM-III-R* edition discussed autistic disorder as a “persistent lack of responsiveness to people” (APA 1987).

The *DSM-IV*, issued in 1994, covered Lorna Wing’s previously mentioned basic triad of impaired social interaction, impaired social communication, and restrictive behavior patterns. However, it also included Asperger’s Syndrome as a separate category, describing individuals with “less severe” symptoms of autism, a general absence of difficulties related to language development, and good cognitive skills (APA 1995).

In terms of prevailing viewpoints in psychological theory in the United States, the 1960s and 1970s saw an increase in the popularity of behaviorism. This naturally laid the foundations for an increase in behavioral treatment. Ole Ivor Lovaas, a Norwegian-American psychologist and professor at UCLA, used the principles of learning theory to modify behavior in children. He proposed a shift from the psychoanalytic perspective to a behavioral one. His approach eventually became known as Applied Behavior Analysis or ABA.

A very labor-intensive approach to treatment which is often covered by insurance, ABA has become a popular and widely used approach in the United States. It is a program that employs the basic ‘laws’ of behaviorism

and learning theory in order to change a child's behavior. It involves parents and educators in the process of changing a child's behavior. This approach to autism was developed by Lovaas after publishing several papers on behaviorism in the 1960s and 1970s. A widely read story in *Life* magazine titled "Screams Slaps and Love" helped to popularize his views. He followed up with a report in 1987 that considered the effectiveness of ABA with autistic children. Prior to this, in 1974, Lovass was connected to the 'feminine boy' project, which involved interventions for gender non-conforming young people. He published his work related to this project in a 1974 article in the *Journal of Abnormal Child Psychology* (Rekers, Lovaas, and Low 1974). As time progressed into the 1990s and more people learned about autism and ABA, it became covered more frequently in the popular media. Some in the autistic community see ABA as a "troubling" form of conversion therapy. Members of the neurodivergent community also express concerns about Tustin, Bettelheim, and Lovass for their use of language that describes autistic children as less than human (Waltz 2008).

In 1988, Dustin Hoffman played an autistic savant in the Academy Award winning film *Rain Man*. Hoffman's character, Raymond Babbitt, was roughly based on Kim Peek, who possessed a remarkable memory. Peek could read entire books, calendars, and maps in a very short time and commit them to memory. For a period of time, it seemed like when someone said they had autism or were autistic, the stock response was "oh, like Rain Man." Some years later, it shifted to "oh, like Sheldon in the *Big Bang Theory*." The answer to both of those responses was usually, "no."

1990 saw the passing of the Americans with Disabilities Act. Many individuals with autism are covered by this law, which prohibits discrimination against people with physical or mental impairments that affect one or more major life activity/activities. In 1993, at a small conference on autism, Jim Sinclair gave his landmark speech, "Don't Mourn for Us," intended for parents of autistic individuals. This speech is discussed in greater detail in the later chapter 'Autism, Gender, and Intersectionality'. It essentially shifted autistic individuals' views of themselves and how their families viewed them - no longer victims to be cured or pitied, they were, for the first time, represented as individuals who communicated and lived in the world differently. It served as a cornerstone for what eventually became the neurodiversity movement (Sinclair 2012).

In 1994, the *DSM-IV* (APA 1994) began to include Asperger's Syndrome as a separate diagnostic category, and in 1996, Temple Grandin (2005) published her first widely received book entitled *Emergence*. Three years

later, in 1998, Judy Singer coined the term ‘neurodiversity’ in her thesis entitled “Odd People In: The Birth of Community Amongst People on the Autism Spectrum: A Personal Exploration of a New Social Movement based on Neurological Diversity”, which she presented to the Faculty of Humanities and Social Sciences at the University of Technology in Sydney, Australia. She stated that the neurologically different comprised a political group, comparable to those of class, race, and gender (Singer, 1998). A year later, she published her ideas on neurodiversity in Marian Corker’s book *Disability Discourse*, placing the term in the field of disability studies (Corker and French 1999; Singer 1999). Later, in 1998, *The Atlantic Monthly* published an article by Harvey Blume that first presented the term to a widespread audience in the popular press. Blume’s article “Neurodiversity, On the Neurological Underpinnings of Geekdom” discussed an earlier article from *Hot Wired* magazine by Jon Katz titled “Geekforce”, a discussion of “neurotypical” people and the idea that the internet is the chosen meeting place for those who aren’t among them (Blume 1998).

Between 1998 and 2001, a controversy emerged over the relationship between vaccines and autism. It centered around the use of thimerosal as a preservative. At the urging of the American Academy of Pediatrics and the United States Public Health Service, the use of this chemical was discontinued in 2001. Several later scientific studies failed to find a cause-and-effect relationship between vaccinations and autism (Hurley, Tadrous, and Miller 2010).

The 2000s marked the beginning of the Autism Acceptance Movement which emerged with, and in many ways powered, the Neurodiversity Movement. In 2006, Ari Ne’eman and Scott Michael Robertson co-founded ASAN, The Autism Self Advocacy Network, an organization that works to advance civil rights, support self-advocacy, and improve public perceptions of autism. They also work to influence public policy, develop autistic cultural activities, train autistics in self-advocacy, and provide information about disability rights. Their motto is “nothing about us without us” (ASAN n.d.).

During the early part of the twenty-first century, there was considerable press about increasing prevalence rates of autism in the United States. In the year 2000, the Centers for Disease Control and Prevention estimated that one in 150 children had some form of autism. In 2008 the estimate grew to one in 68, and in 2020 their estimate was one in 54, with 1.8 percent of children having been identified as having autism spectrum disorder (ASD)

according to the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) (CDC 2020). Recent analysis of data by the CDC indicates that the prevalence rate could be even higher, at almost 2.3 percent (Maenner et al. 2021). International prevalence rates are also under review. A seven-year study of children in Stockholm, Sweden found a prevalence rate of 1.15 percent - similar to that in much of Western Europe (Idring et al. 2012). In South Korea, where a large portion of autistic children are in the mainstream education system, an even higher rate of 2.64 percent was found (Young et al. 2011).

### **Changing Trends in Language**

As perceptions and attitudes toward autism have shifted recently, it is important to consider accompanying trends in language and the way autism and autistic people are referred to. Labels and language are powerful, and we need to take care to use them in a respectful way. Phrasing colors the meaning and perception of what we say and what we write. For this reason, it is important to examine identity first versus person first modes of language in professional writings and discussions. It is worthwhile and important to be sensitive in our use of language when referring to individuals and groups. When unsure of how to use language to describe a condition or individual it is best to ask what their preference is.

For many years professionals in the field of psychology have been encouraged to use person first language. There has been a recent shift in this long-term trend. The APA style manual has traditionally called for "person first language" (APA 2015), emphasizing the person over the disability. For example, this approach would prefer "person with depression" or "person with schizophrenia" to depressive or schizophrenic, or "depressed person" or "schizophrenic individual" when referring to a client or a participant in a research study. Some groups prefer particular ways of referring to themselves, and in those cases, it is appropriate to change standards. Deaf individuals, for example, prefer to be called Deaf with a capital D rather than a person with hearing loss. This is an example of a cultural preference. According to the Autism Self Advocacy Network many in the autistic community prefer "autistic individual" to "person with autism." Autism is part of a person's identity. They would prefer not to hear phrases like, "A person who is afflicted with autism," or "a person who suffers from autism." This is analogous to the way you would not refer to a person who is a Catholic as a person with "Catholicness."