"I loved this book! Respect and empathy infiltrate every chapter. . . and inform us how to appreciate and include all kids." – praise for the previous edition

"You're Going to This Kid!"

Teaching Autistic Students in the Inclusive Classroom

THIRD EDITION



Excerpted from You're Going to Love this Kid Teaching Autistic Students in the Inclusive Classroom, 3e by Paula Kluth



Praise for You're Going to Love This Kid!: Teaching Autistic Students in the Inclusive Classroom, Third Edition

"Dr. Kluth has done it again! *You're Going to Love This Kid* should be required for all inclusion advocates and teachers. Practical and immediately useful information and resources abound in a book that celebrates the assets and strengths of children with autism."—**Jennifer A. Kurth, Ph.D., Associate Professor, Department of Special Education; Associate Director of Interdisciplinary Training, Kansas University Center on Developmental Disabilities, the University of Kansas**

"The practical helpfulness—from the big, broad, complicated idea of explaining ramifications of the law to the everyday nuts and bolts of setting up an accessible classroom to provide inclusive access—is quite evident. What is most helpful is something Kluth has always done well—understanding and starting with who autistic people are and how that impacts all of everything for autistic people. Because of this starting point and focus throughout, Kluth leads us all down the path so that a truly inclusive experience where everyone involved thrives can be had by all."—Judy Endow, LCSW, author, international speaker, and first autistic person to receive the Autism Society of America's Cathy Pratt Professional of the Year Award

"Pure reader bliss in an easy-to-digest format that is authentic, straightforward, and inspiring! Chapter after chapter you'll be drawn into deeper levels of learning through research, relevant content, quotes from the *voices* of autistic individuals, and multiple resources that can be used immediately. This book should be on every educator's year-round reading list!"—**Terri Doane Savage, Ed.D., Executive Director for Special Education, Howard County Public Schools, Consultant, and Coach**

"Warning: Once you learn these practical and inclusive strategies for welcoming students with autism in your school, you'll never be satisfied with anything less! This update on Kluth's classic text is a must-have for any teacher who is building an inclusive classroom."—**Andrea Ruppar, Ph.D., Associate Professor, University of Wisconsin–Madison**

"Paula Kluth's superb book is a must for every professional, family member, and individual with autism. Current, thoughtful, sensitive, and creative beyond imagining with practical, time-saving resources. Paula is helping us to change the world for the better: one student, one classroom at a time."—**Kate McGinnity, MS, autism consultant and presenter, coauthor of** *Walk Awhile in My Autism* and *Lights, Camera, Autism*

"If you are looking for resources on how to successfully include students on the autism spectrum, this book is your guide, full of practical strategies that are well researched. Throughout this text, the voices of autistic people are heard; they lend important credibility to the content and offer a more personal and authentic perspective. The planning worksheets and forms are very useful and practical; they will assist educators, administrators, and parents to successfully include autistic students in general education classrooms and school. A must read for all educators and parents."—**Mary Falvey, Ph.D., Emeritus Professor, California State University, Los Angeles**

"Dr. Paula Kluth has long been a champion for respectful, effective, and student-centered educational approaches in inclusive settings. She has the gift to think out of the box and urges educators, clinicians, and families to push back against 'deficit-checklist' approaches to celebrate the great potential for every student to thrive academically, socially, and emotionally. In this edition of her landmark book, she brings in new strategies and partners with gifted collaborators... Paula once again is energizing the paradigm shift that enhances the important work of professionals and improves quality for families and so many children." **—Barry M. Prizant, Ph.D., CCC-SLP, author of** *Uniquely Human: A Different Way of Seeing Autism,* Adjunct Professor of Communicative Disorders, University of Rhode Island

"A must read for all educators. Centering in strengths is a true game changer. Paula Kluth provides practical strategies to use in the classroom tomorrow, while building the case for inclusion and belonging for each and every student. This book builds capacity and inspires."—Jennifer Spencer-Adams, Ed.D., Assistant Superintendent, West Linn-Wilsonville School District, author of *Leading for All: How to Create Truly Inclusive and Equitable Schools*



Teaching Autistic Students in the Inclusive Classroom

THIRD EDITION

by

Paula Kluth, Ph.D. River Forest, Illinois

 $with \, invited \, contributors$



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About the Downloads

Purchasers of this book may download, print, and/or photocopy the planning worksheets and forms in this book for educational and professional use.

To access the materials that come with this book:

- 1. Go to the Brookes Download Hub: http://downloads.brookespublishing.com
- 2. Register to create an account (or log in with an existing account)
- 3. Filter or search for the book title You're Going to Love This Kid!: Teaching Autistic Students in the Inclusive Classroom, Third Edition

Paula Kluth, Ph.D., Consultant, Author, Advocate, and Independent Scholar

Paula (she/her) is a consultant, author, advocate, and independent scholar who works with teachers and families to provide inclusive opportunities for students with disabilities and to create more responsive and engaging schooling experiences for all learners. She is a former K–12 special educator who has served as a classroom teacher, co-teacher, and inclusion facilitator. Paula has also been a university professor and taught courses on both inclusion and disability studies. Most recently, Paula's work has centered on helping teachers and administrators educate all students in their schools and classrooms. She also frequently works with families and advocacy groups to support goals related to inclusion. In addition to inclusive education and autism, her professional interests include universal design for learning, co-teaching, and educating students with complex support needs.

Paula is the author or coauthor of 15 other titles including Universal Design Daily, 30 Days to the Co-Taught Classroom (with Dr. Julie Causton), Don't We Already Do Inclusion?: 100 Ideas for Improving Inclusive Schools, and Just Give Him the Whale: 20 Ways to Use Fascinations, Areas of Expertise, and Strengths to Support Students with Autism (with Dr. Patrick Schwarz). She is also the author of a few books for children, including Coaster, a story of a puppy with wonderful wheels.

You can find out more about Paula's work by visiting her website, inclusionrules.com, or by connecting with her on social media (@paulakluth).

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Christi Kasa, Ph.D., Professor and Director of the Office of Inclusive Services, University of Colorado

Christi Kasa, Ph.D. is Professor for the Department of Teaching and Learning and Director of the Office of Inclusive Services in the College of Education at the University of Colorado. Her teaching, research, and consulting are guided by her passion to create successful inclusive schools. Dr. Kasa's expertise is in the areas of inclusive education and strategic systems change to end the segregation of disabled students.

Eileen Yoshina, M.Ed.

Eileen Yoshina has worked in educational equity for the last 25 years. She currently works to support efforts to diversify the educator workforce in the Puget Sound region of Washington state.

Foreword

Paula Kluth is probably the best person around to write a book about how to support children with autism in public schools. She knows the first three rules of education as well as anybody I can think of.

Rule number one is to listen before you talk. And by listen, I don't just mean pretend to listen, but really listen as if you are ready to be told an important secret. The second rule is to love your students. And by love, I don't mean like a mom or a pet owner; I mean the love between two people who need each other to make their way through the hard times and the easy times together. The third rule is that there are no rules. And that doesn't mean that nothing really matters; it means that people matter too much to try to make rules about what they need.

So, welcome to this wonderful book. By the time you finish it, you will know what a blessing you might become for a child who has the good luck to meet you.

Eugene Marcus Syracuse, New York

Author's note: Eugene Marcus is a man with autism who believes in his own rights and those of others with and without disabilities. He is an alumnus of Syracuse's inclusive school system. He has co-taught courses at Syracuse University and has given lectures on topics ranging from communication to inclusion to autism.

On the morning of my first day of teaching, I was told I would be working with a 6-year-old student with autism named Jacob. I was given dozens of files to review. I marveled at the stacks of reports, evaluations, observations, clinical assessments, work samples, and standardized test results. I couldn't believe a child so small could have so many "credentials." As I reviewed these materials, my feelings changed from stunned to overwhelmed to terrified. Jacob's paperwork was filled with comments and observations about his inability to be a successful learner. I paged through document after document spying phrases such as, "He can't ...," "He doesn't ...," and "He won't...." Page after page detailed his challenging behaviors, skill deficits, learning needs, and communication problems. I was dazed. I was scarcely 22 years old, I had only recently graduated from my teacher preparation program, and I remembered little from the one or two lectures I had attended on autism.

Before I could run to the bathroom to dry the stress-related tears forming in my eyes, I heard my name on the loudspeaker and was beckoned to the school office. I was being called to an impromptu meeting with my visiting supervisor. I grudgingly made my way down the hallway only to be met halfway by a grinning and extremely animated school administrator. Dr. Patrick Schwarz seized me by the shoulders and bellowed, "So, you're going to be Jacob's teacher! That's fantastic. You're going to *love* this kid!" I would find out later that Dr. Schwarz had paid a visit that day specifically to help me better understand my new student and wade through the piles of not-so-positive information about him.

This inspirational leader could not have been more accurate in his assessment of Jacob or the future I would have with this young student. Throughout the next few months, Dr. Schwarz, the principal, our school's occupational therapist and speech-language pathologist, my general education colleagues, Jacob and his family, and the other students in the school all collaborated to create an inclusive environment and accessible learning experiences in the first-grade classroom. Administrators shifted classroom schedules to accommodate Jacob's need for a recess break early in the day; classmates worked to learn Jacob's communication system; teachers created materials and invented lessons that intrigued and engaged their new student; Jacob's family shared their expertise and gave suggestions for making him comfortable in his new school; and Jacob worked daily to meet new friends and learn classroom routines.

Although Jacob was nonspeaking, occasionally struggled with challenging behaviors, regularly experienced sensory sensitivity, and needed a wide range of adaptations to engage in curriculum and instruction, he was soon participating and succeeding in all aspects of school life. Through this energetic, precocious, and unique 6-year-old, I learned how to be a teacher not only of autistic students but also of all learners with and without disabilities in inclusive classrooms.

An important piece of this story is obviously the role of my former administrator, Dr. Schwarz. His positive attitude and encouraging behaviors influenced my impression of Jacob, inspired me to learn about students in holistic ways, and prompted me to study more about autism.

Unfortunately, the perspective and attitude offered by my administrator is somewhat rare. The dominant paradigm in special education has historically been centered on labels, deficits, and clinical understandings of difference. This paradigm was evident as I looked through Jacob's files and is still reflected in many college textbooks, research studies, and popular media sources that introduce preservice teachers to autism.

Preface

I believe Jacob's story is an appropriate way to illustrate an alternative approach to educating students on the autism spectrum. Dr. Schwarz's understanding of Jacob was hopeful, holistic, and strengths-based. Jacob's success at school cannot be separated from this understanding. This story hints at the possibilities that exist when educators see students as a necessary part of the school community, view inclusive schooling as a possibility for all learners, and understand support as a process.

The book provides concrete examples of how to create inclusive schools using this lens. The chapters cover ideas for planning lessons, engineering safe and comfortable classrooms, providing communication opportunities, supporting interfering behaviors, and more. Drawing on classroom observations, current research, and my own experience as an elementary and high school teacher, I explore pragmatic ways of making schools safe, appropriately challenging, and accessible for autistic students.

As readers of the second edition will notice, this third edition has more material and several new features. The reason for making the book a bit longer was simply to add in more strategies and ideas. For instance, several new illustrations and photographs can be found throughout the book, and additional quotes from autistic people have been added to enrich the suggestions in several chapters. New features are also a big part of this edition. Readers will now find a bulleted organizer and a set of discussion questions in each chapter as well as several resources that can be found both in the book and in a printable download on the publisher's website (see the About the Downloads page).

As in the first two editions, the book consists of 12 chapters. Each chapter is concerned with a different school issue/structure (e.g., lesson planning, collaboration) and provides concrete examples of how autistic students can be supported.

Chapter 1 includes definitions and characteristics of autism and illustrates how those on the spectrum experience differences, such as sensory sensitivity and movement disorders.

Chapter 2 provides information about how teachers and school leaders can work toward inclusive education in both elementary and secondary schools. This chapter also outlines the federal laws related to special education.

The role of the teacher is reviewed in Chapter 3. This chapter explores some of the values and beliefs that support the development and sustenance of inclusive schools.

Chapter 4, coauthored with Eileen Yoshina, features the voices of families and gives ideas for partnering with parents and caregivers in respectful and meaningful ways.

In Chapter 5, coauthored with Paula Aquilla, I share specific strategies helpful in the creation of a positive and comfortable educational environment. Ideas for arranging and organizing classrooms are provided, as is information on adjusting classroom lighting, seating, and space.

Chapter 6 contains ideas for building classroom community and encouraging the development of social relationships both during the school day and beyond.

If students do not have reliable communication or struggle to express themselves effectively, then every other aspect of their education program is at risk. Chapter 7 illustrates different ways that student communication can be bolstered and supported in the inclusive classroom. Different types of augmentative and alternative communication are also described in this chapter.

In Chapter 8, I explore with my coauthor, Dr. Kelly Chandler-Olcott, why some students with unique learning profiles may not be receiving the literacy instruction they need or deserve. We also explore several recommendations for teaching literacy to autistic students.

Behavior is the focus of Chapter 9. Here, behavior is explored from an alternative perspective. Instead of examining how to stop or "treat" behavior, I present it as something that must be understood in context and interpreted using the words and experiences of autistic people. Positive ways to support a range of behaviors are provided throughout the chapter.

Chapter 10 contains tools and structures to assist educators in creating lessons appropriate for students on the autism spectrum and for all learners in inclusive classrooms. Specifically, these pages feature a step-by-step planning process featuring the principles of universal design for learning.

Preface

Chapter 11 is coauthored with Dr. Christi Kasa. This chapter is a collection of practical teachertested ideas (e.g., visuals, movement breaks) that can be used with all students in the classroom, with a handful of students, or with any individual student who needs something extra or different in terms of classroom materials, daily instruction, or curriculum.

Collaboration and co-teaching are the focus of Chapter 12. This chapter gives educators suggestions for working with all team members and tips for both co-teaching and structuring the collaborative classroom.

I believe this book is unique in that most textbooks focused on teaching autistic students

- Do not focus primarily on inclusive classrooms
- · View autism from a medical model or a deficit perspective
- Treat communication, behavior, and learning problems as things that "belong" to students instead of as issues that must be understood in context and within relationships
- Lack perspectives, ideas, and suggestions from autistic individuals and their families

"You're Going to Love This Kid!" alternatively

- · Focuses exclusively on inclusive schooling
- · Views inclusion as both an ideology and a pedagogy
- Proposes sensitive new ways to see and understand autistic students
- Outlines how autistic students can participate in curriculum and instruction in the inclusive classroom and clearly illustrates appropriate supports
- Includes frameworks, approaches, and strategies useful for teachers, administrators, and other school personnel (e.g., therapists, counselors, paraprofessionals)
- · Prominently features the voices of autistic people

Despite the progress that has been made across the country in inclusive schooling, too many students with autism are still being excluded from public schools. In many cases, teachers want to support these learners but do not have the support, knowledge, or skills to do so. This book is written for this audience—those committed to inclusive schooling and looking for answers.

You will notice that the terminology used to describe students in this edition of *"You're Going to Love This Kid!"* has largely changed from person-first (e.g., "a student with autism") to identity-first (e.g., "an autistic student"). This change has been made to reflect the preferences of many autistic people who have shared that, although they understand that person-first language emerged to support and honor disabled people and combat stereotypes and one-dimensional views of autism (Brown, 2011; Dwyer, 2022), this way of speaking and writing can actually be harmful as it problematically separates autism from the individual (Botha et al., 2021; Brown, 2011; Okundaye, 2021; Sequenzia, 2016; Sinclair 1999).

To some, person-first language also communicates that autism is something negative that should be diminished or downplayed as in, "He has autism, but he is so much more than his autism." According to many advocates and self-advocates in the field of autism, this mindset is not only potentially hurtful, but also misleading. In fact, Jim Sinclair noted in his landmark 1999 essay on the topic that autism is so essential to his being that it cannot be understood as just one piece of him. Instead, he explains, autism is integrated into all that he is:

Saying "person with autism" suggests that even if autism is part of the person, it isn't a very important part. Characteristics that are recognized as central to a person's identity are appropriately stated as adjectives, and may even be used as nouns to describe people: We talk about "male" and "female" people, and even about "men" and "women" and "boys" and "girls," not about "people with maleness" and "people with femaleness." . . . We describe important aspects of people's personalities in terms such as "generous" or "outgoing," [not as] "person with generosity" or "person with extroversion." [Autism] affects how we relate to others and how we find places in society. It even affects how we relate to our own bodies. If I did not have an autistic brain, the person that I am would not exist.

This view of autism and corresponding terminology change may be new to some, but it is not new. It has, however, gained a lot of traction in the last few years. In fact, in a survey of language conducted by the Organization for Autism Research (2020), more than 80% of the respondents (e.g., self-advocates, parents, professionals) indicated that they preferred identity-first language over person-first language.

Having shared all of that, it should be noted that autistic people are individuals. Therefore, their language preferences are not uniform. Some still do prefer the use of person-first language or other ways of describing their diagnosis, identity, or uniqueness (Bury et al, 2020; Dwyer, 2022). Therefore, you will see that although identity-first language is used frequently in these pages, you will also find some uses of person-first language. Some uses of the term "on the spectrum" instead of "autism" have also been included to further acknowledge these diverse preferences.

This book was created with the intention to listen to autistic voices and develop strategies around their recommendations. A shift in language, therefore, was a necessary and important update to this third edition.

References

- Botha, M., Hanlon, J., & Williams, G. L. (2021). Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti. https://doi.org/10.1007/s10803-020-04858-w
- Brown, L. (2011, August 4). The significance of semantics: Person-first language: Why it matters. https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html
- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It defines who I am" or "It's something I have". What language do [autistic] Australian adults [on the autism spectrum] prefer? https://doi.org/10.1007 /s10803-020-04425-3
- Dwyer, P. (2022). Stigma, incommensurability, or both? Pathology-first, person-first, and identity-first language and the challenges of discourse in divided autism communities. *Journal of Developmental and Behavioral Pediatrics*, 43(2), 111–113.
- Okundaye, J. (2021, April 23). Ask a self-advocate: The pros and cons of person-first and identity-first language. https://www.massadvocates.org/news/ask-a-self-advocate-the-pros-and-cons-of-person-first-and-identity -first-language
- Organization for Autism Research. (2020, September 30). 1,000 people surveyed, survey says . . . https://researchautism.org/1000-people-surveyed-survey-says
- Sequenzia, A. (2016, November 10). Person first language and ableism. https://ollibean.com/person-first -language-and-ableism
- Sinclair, J. (1999). Why I dislike "person first" language. https://autismmythbusters.com/general-public /autistic-vs-people-with-autism/jim-sinclair-why-i-dislike-person-first-language

I am indebted, first and foremost, to all of the students with whom I have worked, but especially to Jacob, Jason, Andrew, Franklin, Paul, Caleb, Kelsey, and Michael. You were the first to teach me about autism.

Many other friends and colleagues on the autism spectrum have helped me to think critically about disability, ability, and autism, including Roy Bedward, Jamie Burke, Judy Endow, Kathy (Xenia) Grant, Stephen Hinkle, J. P. Hussman, Hesham Khater, Jon Micheal, Barbara Moran, Jerry Newport, Ron Sandison, Christie Sauer, Dr. Stephen Shore, Sean Sokler, Mark Van Boxtel, and Dr. Lianne Holliday Willey. The families of autistic people have also been incredibly generous with their time and energy; their stories and teachings have been invaluable. Special thanks to Sheree Burke, Robin Chen, John Hussman, Cori Mohr, and Pat Wilson.

I would like to thank the staff of Kruse Education Center in Orland Park, Illinois. The teachers at Kruse taught me how to teach and crafted many of the strategies shared in this book. I am especially grateful for the support of Barbara Schaffer and Peg Sheehan. Unending gratitude also goes to Patrick Schwarz, who first told me, "You are going to love this kid!" The staff at Stoner Prairie Elementary School in Verona, Wisconsin, also taught me a great deal about inclusive schooling—especially my second-grade team and, specifically, Erin DiPerna. More recently, my work has been inspired by many educators in Chicago Public Schools, including those who invited me to visit their virtual classrooms in the early days of the COVID-19 lockdown.

My work in this book is inspired by several mentors: Dr. Lou Brown, Dr. Alice Udvari-Solner, Sue Rubin, Eugene Marcus, Dr. Anne Donnellan, Dr. Douglas Biklen, and Dr. Mayer Shevin. I am so grateful for their contributions to the field.

I am fortunate to have some generous friends who read pieces of this manuscript and gave thoughtful feedback: Dr. Kelly Chandler-Olcott, Dr. Tracy Knight, Matt Grant, Kathy Kurowski, Kate Zagorski, and Eileen Yoshina. Thank you all so much!

A book with the title *"You're Going to Love This Kid!"* must include an acknowledgement for the two kids I love the most, Erma and Willa. Girls, thank you for your hugs, your support, and all of the help with writing-related errands and chores. I hope you will someday write your own books about things you love (e.g., whales, rescue dogs, genetics)! And, a big "I couldn't have done it without you" to Todd. Your tech support is second to none. Your grace is unmatched. And your ability to put up with markers and manuscripts everywhere is absolutely astounding.

Finally, I am grateful to those at Paul H. Brookes Publishing Co. for the care that they invested in this book (again)! In particular, I want to thank Sharon Larkin for Snickers, Sharpies, and painstakingly putting all the supports in place for this project; Tess Hoffman for her creativity and steadfast commitment to creating the best possible version of this book; Lynda Phung-Wheeler for her patience, guidance, and help with a seemingly endless number of revisions; and the entire design team (including the incredibly talented contributor, Kristin Wiens) for the many trips back to the drawing board—it was appreciated more than you know! To Franklin Wilson, a gifted and patient teacher, and to Pat Wilson, my teacher's teacher

"Autistic children don't deserve to be molded into someone they are not. They deserve to learn and grow and feel comfortable about themselves. Their worlds can expand to include new experiences, and they can become teachers, opening others to their viewpoints."

66

-Jasmine Lee O'Neill (1997, p. 1)

"



LEARNING GOALS

- Describe the medical model of autism.
- □ Explain why it is imperative to learn about autism from autistic people.
- Explain some of the gifts and strengths of autism (according to autistic people).
- □ Summarize problems autistic people may experience with testing, formal assessments, and evaluation.
- Describe common differences experienced by autistic people (e.g., sensory differences, communication differences).

few years ago, a teacher called me to ask for advice about a new student, an autistic girl, in her eighth-grade classroom. She wanted to know how to set the student up for success. She was particularly concerned about the other students; she thought they needed to learn a bit about autism in order to be sensitive to their new classmate's needs. She wanted to know if I thought it was a good idea to have the school social worker do a classroom presentation on the topic. She mentioned that she was also considering inviting the student's parents to come in and share some information about their daughter. I asked her if the student had a reliable way to communicate. The teacher said that the girl could speak and was quite verbal and engaging. I then asked about the student's thoughts on the idea. I specifically wanted to know if this middle schooler wanted the social worker or her parents to visit the classroom on her behalf. The teacher answered, "I don't know. I didn't ask her."

With so many books, articles, podcasts, YouTube channels, training programs, and autism-related professional development activities available to educators, teachers may overlook the most important resource of all when it comes to learning about autism: students. Some learners can teach us directly and others can teach us through shared experiences and interaction. Mr. Rusch, one of my former colleagues, learned this lesson when he was told over the summer that he would have an autistic student in his classroom that fall. Throughout August, he called me constantly. He was very nervous about teaching this student and repeated one request over and over again: Can you get me a textbook on autism? I resisted, fearing that he would have one of two responses. He would either 1) see the medical model definitions of autism and fear he was not qualified to teach the student or 2) read the text and declare himself prepared. Neither of these outcomes, I reasoned, would be good news for Ronnie, his new student.

I scrambled to find appropriate materials for Mr. Rusch, but this was 1992, and there were few resources that were focused on the words and experiences of autistic people and none that were related even remotely to teaching in inclusive settings. Before I could figure out how to properly support Mr. Rusch, he called to tell me that Ronnie's family had invited him to their home. Mr. Rusch accepted the invitation, his first home visit in 25 years of teaching.

When he came back to school, he was feeling far more confident. He told me all about Ronnie's unique way of communicating (expressing himself using speech, gestures, sign language, and even a few songs), his ability to play complex, multistep video games, and his interest in building things out of household objects. He also shared a story about an experience that shifted his understanding of Ronnie's potential and ability. Apparently, during the visit, Ronnie had walked around the family's living room and fiddled with a speed cube while "watching" a Discovery Channel show on submarines. Afterwards, he was able to answer questions on even the smallest details shared in the show. This "fidget, pace, and learn" ability that Ronnie demonstrated stunned Mr. Rusch.

In getting to know Ronnie as an individual, my colleague was practicing what Kliewer and Biklen (2001) called *local understanding*, which is "a radically deep, intimate knowledge of another human being" (p. 4). These researchers explained that relationships are key when it comes to supporting students with unique learning profiles as they allow teachers to notice "demonstrations of understanding that are otherwise dismissed or disregarded by more distant observers" (p. 4). In other words, someone who has not spent time with Ronnie across environments, talked to his family, or asked him questions about submarines might see his pacing and fidgeting as problematic. A teacher who knows him, however, might see those behaviors very differently. They might conclude that Ronnie doesn't need to "sit and get" to learn; they might also hypothesize that movement actually *helps* Ronnie listen and even that this student may be more complex and competent than he often appears to be.

Getting to know Ronnie personally certainly helped Mr. Rusch appreciate his student's many strengths and abilities. It also enabled him to generate effective supports for Ronnie and serve as an advocate for him. When the technology teacher suggested that learning to use a new software program would be too difficult for Ronnie, Mr. Rusch objected, citing his student's video game prowess as an example of his abilities in problem solving. The technology teacher agreed to include Ronnie in the lesson and was pleasantly surprised when Mr. Rusch proved him wrong. And when the speech-language pathologist (SLP) could not get Ronnie to use a new communication tool during a writing lesson, Mr. Rusch suggested she switch the essay topic and let him write about the "found object" creations he constructed with his dad. This new topic instantly inspired Ronnie to try the tool, much to the surprise and delight of both Mr. Rusch and the SLP.

In this chapter, I introduce readers to the topic of autism and deliberately start by sharing a story about the importance of learning with and from your students. Mr. Rusch and Ronnie serve as a reminder that while learning about autism is important, the best lessons will come from the individual students who enter your classroom. Therefore, in this chapter, I not only define autism from the medical model but also share interpretations of it from those who know it best—autistic people. Following that, I explore and question labels, assessments, and descriptions of autism. This chapter then ends with information about the main characteristics of autism, complete with quotes, perspectives, and reflections from autistic children and adults.

Defining Autism

One of the first things a teacher wants to know when they learn that a student with autism is coming into the classroom is, "What is autism?" Autism is difficult to define because it is complex and our understanding of it is constantly evolving. Further, as Kathy Xenia Grant, an autistic woman,

shares in a documentary film I codirected, *"We Thought You'd Never Ask": Voices of People with Autism* (Hussman et al., 2009), no two individuals experience autism in the same way: "Autism is so complex because it's a spectrum disorder. It's like saying, 'Define the Middle East.' What country? Iran? Iraq? Syria? Autism is the same way."

Although autistic people may share some characteristics, they tend to have more differences than commonalities. For example, some individuals welcome touch; others find it painful. Some students crave social interaction; others need more space and time alone. Some are extremely talk-ative; others cannot reliably use speech. It is critical to remember that autistic students vary widely in experiences, skills, abilities, interests, characteristics, gifts, talents, and needs. Autistic scholar Stephen Shore, is fond of saying, "If you know one person with autism, you know one person with autism." For this reason, I offer several descriptions of autism and interpretations of the diagnosis in this chapter.

Understanding Autism: From the Experts

I begin with the most important and useful definitions of autism—those that come from autistic people, individuals who experience sensory, movement, and communication differences every day:

Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive: It colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you'd have left would not be the same person you started with. (Sinclair, 1993, p. 1)

66 Eagerness to be like others didn't make Pinocchio real—it turned him into a donkey! And eagerness by parents to cure autism or retardation or compulsiveness will not drive great distances toward the final solution to the actual problem. Because the person who believes "I will be real when I am normal" will always be almost a person, but will never make it all the way. (Marcus, 1998, p. 2)

66 When I learned that autism was neurological and was related to sensory processing, that made sense to me because so many things bothered me that didn't bother other people. I just didn't develop and function like other people did. And I learned that the reason it was hard for me to control my behavior was because life was much more intense for me. (Moran, as cited in Hussman et al., 2009)

66 Autism means having to watch how I feel every second that I am awake. Autism means having challenges when I leave the room fearing that others will say unkind things about me to other people. Autism means being dateless on weekends as well as constant loneliness, only watching TV on Saturday night. Autism means not being able to fit in on social peer relations. However, autism, in my case, means that I have a calendar memory for birthdays, being articulate and having skills. I, all in all, would rather be autistic than normal. (Ronan, as cited in Gillingham, 1995, p. 90)

66 Some aspects of autism may be good or bad depending only on how they are perceived. For example, hyperfocusing is a problem if you're hyperfocusing on your feet and miss the traffic light change. On the other hand, hyperfocusing is a great skill for working on intensive projects. This trait is particularly well suited to freelancers and computer work. I would never argue that autism is all good or merely a difference. I do find that my autism is disabling. However, that doesn't mean that it is all bad or that I want to be cured. I may not be altogether happy with who I am, but that doesn't mean I want to be someone else. (Molton, 2000, p. 2)

Perhaps the most striking aspect of the definitions put forward by autistic people is that they often look so different from those offered by the medical and scientific communities. Although those on the spectrum often note their struggles in descriptions of autism, they also commonly mention—or even center on—associated gifts or abilities. Certainly, this way of seeing autism is not embraced by every autistic person, but I highlight the optimism and pride that many include

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in their definitions because these perspectives do not get enough attention. Consider a few ways in which some individuals describe the gifts associated with autism:

I believe Autism is a marvelous occurrence of nature, not a tragic example of the human mind gone wrong. In many cases, Autism can also be a kind of genius undiscovered. (O'Neill, 1999, p. 14)

66 My autism increases my ability to acquire information and it increases my ability to take disparate pieces and create an abstract form that other people can't conceive or visualize. (Thurman, 2016, p. 172)

66 We can describe a situation like no one else. We can tell you what intangibles feel like and secret flavors taste like. We can describe for you, in unbelievable depth, the intricate details of our favorite obsessions. (Willey, 2001, p. 29)

66 I think [autism] is another perspective on the world. It's certainly helped me with the mathematical side of things. I find it very easy to think in highly abstract terms. I can solve a Rubik's Cube in two minutes. (Molloy & Vasil, 2004, p. 40)

For someone like me, where I do face a lot of challenges as a result of not being able to order off the same menu [as a neurotypical person], I still wouldn't choose to have a different menu after having lived with this one. I'm really appreciative for the way that I think. Even if I had new opportunities, I feel like I would lose as well. It's not a win or a win-win—it's a loss. And I wouldn't like the losses. Some of the benefits I wouldn't want to lose are not being able to be as easily influenced by emotion and my memory. There are other benefits, like methods of thinking; I seem to have more visual thinking than other people, and that's a benefit. (Fleming, 2021, p. 27)

[At my job] I can sit down and during those timetabled hours work with little movement away from the task. I believe the unwavering focus to a subject has aided me academically, my different approach to thinking has also aided me in this way and of course I wouldn't have my job without it and the comfortable life. (Russell, 2019, p. 128)

Glancing at the ground as I walked along, I noticed some movement at my feet and saw the last exit moments of a cicada crawling out of a hole in the ground. I watched this creature transform before my eyes from a dull brownish-green bug into a beautiful bright green and gold, singing creation. The process took only one and a half hours. I have since heard that people thought my standing in the heat for one and a half hours to watch an insect was a crazy thing to do. I think it is they who are crazy. By choosing not to stand and watch, they missed out on sharing an experience that was so beautiful and exhilarating. (Lawson, 1998, p. 115)

Understanding Autism: The Medical Model

As of 2023, when this book was published, autism is diagnosed not by a blood test or other biomarker, but by a person's developmental history and behavior. Therefore, the process may be quick for some but slow and painstaking for others. Some children are diagnosed as toddlers during a single visit to a neurologist, and others have several evaluations before being identified as autistic.

The process of diagnosis is subjective, and understandings of autism have been anything but static in the last several decades. What autism is and what it means is constantly being studied and debated by scholars, researchers, physicians, clinicians, psychologists, and by autistic people themselves. Put more succinctly, the following definitions or labels are not fixed realities but instead represent efforts to categorize and consider the difficulties these individuals encounter, the behaviors they exhibit, and the experiences they report. For this reason, two students with the same exact diagnosis may have very different abilities and challenges. Therefore, a student's label should never drive curriculum, instruction, and supports; any child's educational program should be based on their individual needs.

The Autism Spectrum

Autism is often referred to as a spectrum—meaning different people experience it in different ways and its symptoms can occur with varying degrees of intensity. Autism was first described in the 1940s by American psychiatrist Leo Kanner, and it is one of the most common developmental disabilities in children. According to the Centers for Disease Control and Prevention (2022), approximately 1 in 44 of American children are on the autism spectrum, which is significantly higher than the estimate just 20 years earlier in 2000 of 1 in 150. Autism spectrum disorder (ASD) is reported to occur in all racial, ethnic, and socioeconomic groups. It can sometimes be identified before a child turns 18 months, but it is also not terribly uncommon for students to be diagnosed as autistic in the pre-K years and beyond.

Key changes were made in the diagnosis of autism in May of 2013. A single diagnosis of ASD replaced different subcategories that were used previously—autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS). According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision* (DSM-5-TR; American Psychiatric Association, 2022), autistic individuals will have persistent deficits in three areas of social-communication and interaction. They are

- Social-emotional reciprocity (e.g., struggles with turn taking)
- Nonverbal communication used for social interaction (e.g., exhibits gaze avoidance)
- The development and maintenance of relationships (e.g., demonstrates difficulties adjusting behavior to suit various social contexts)

Plus, autistic individuals will demonstrate at least two of four different types of restricted, repetitive behaviors, interests, or activities including

- Stereotyped or repetitive motor movements, use of objects, or speech (e.g., uses echolalia, engages in hand flapping)
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of behavior (e.g., has difficulties with transitions, eats lunch items in the same order each day)
- Highly restricted, fixated interests that are unusual in intensity or focus (e.g., carries a favorite object at all times, talks a lot about a special interest such as weather or elevators)
- Sensory differences (e.g., reports sensitivity to light or sound, avoids many foods)

Figure 1.1 provides more details of the DSM-5-TR diagnostic criteria for autism.

Diagnoses Related to Autism

A few other labels in addition to autism are given to people who have autism-like characteristics. Sometimes students do not meet the DSM-5-TR criteria, but they do have learning, communication, behavioral, or other differences and need supports similar to those provided to students on the spectrum. Social-communication disorder (SCD) is one diagnosis that students evaluated for autism may receive. It does not co-occur with autism because an autism diagnosis includes social and communication differences. Rather, it is a diagnosis that is understood to be related to autism, and students with SCD may have many of the same needs as those with autism.

Students with Rett syndrome, Williams syndrome, fragile X syndrome, and Landau-Kleffner syndrome may also share characteristics with those on the spectrum. Their teachers may, therefore, benefit from the strategies and ideas shared in this book.

Understanding Autism: Gender

Discussions on gender and autism were almost non-existent in the 20th century; girls were scarcely recognized in research or even in descriptions and definitions of autism. Issues of gender identity

Diagnostic Criteria for Autism Spectrum Disorder

To meet diagnostic criteria for autism spectrum disorder according to DSM-V-TR, a child must have persistent deficits in each of three areas of social communication and interaction (see A.1. through A.3.) plus at least two of four types of restricted, repetitive behaviors (see B.1. through B.4.).

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples are illustrative, not exhaustive; see text):
 - 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 - 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 - 3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
 - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 - 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Figure 1.1. Diagnostic criteria for autism spectrum disorder. (Source: American Psychiatric Association, 2013.)

and gender diversity have also been missing from conversations on autism. These topics are now emerging in a range of studies, in the media, and, of course, in schools.

Autistic Girls

It is commonly reported that autism is four times more likely to occur in boys than in girls (Centers for Disease Control and Prevention, 2022), but some researchers and authors challenge these numbers, claiming that spectrum-related characteristics may simply look different or be perceived differently in girls (Attwood, 2007; Hill, 2009; James, 2018; Milner et al., 2019; Nichols et al., 2009; O'Toole, 2018; Szalavitz, 2016). A 2012 study by Katharina Dworzynski and her colleagues compared the occurrence of autism traits and formal diagnoses in a large, population-based sample of children. They found that if boys and girls had a similar level of such traits, the girls needed to have either more behavioral problems or a perceived significant intellectual disability, or both, to be diagnosed with autism. This finding suggests that clinicians may be missing the diagnoses of girls who do not present with classic symptoms of autism.

There are several possible reasons for these missed diagnoses. Jennifer Cook O'Toole (2018), author of *Autism in Heels*, shared that autism history may hold an answer:

In the early days of autism research—the foundational days really—teams of all-male scientists, like doctor Hans Asperger, observed all-male patients, mostly children. Eventually, those clinicians' notes became the basis of the autism profile. Logically, more boys fit criteria that came from studying and describing boys. No wonder I couldn't find my reflection. How was a catalog of autism spectrum characteristics based on little boys in pre-war Vienna going to help me? In

twenty-first-century suburban America. In a minivan. And bra. With a predisposition toward glitter. (pp. 4-5)

Many accounts of autism and research studies on autistic people indicate that autistic girls often present differently than boys. For instance, they do not seem as likely to show the extreme interest in transportation, gadgets, or computers that boys do; they may have interests, but if their "favorites" are age-appropriate and common (e.g., pop stars), then the "special interest" box on the evaluation may remain unchecked. Autism researcher Kevin Pelphrey noticed that his own daughter, a child on the autism spectrum, did not stand out in this area as she had adopted special interests such as Disney characters and American Girl dolls—topics that were typical for girls her age and shared by many children without identified needs (Szalavitz, 2016).

The social differences girls experience may also look different or just be more acceptable than those reported by or observed with boys. For instance, a boy who struggles with social situations may retreat to the edge of the playground to read or just daydream. If pervasive, this preference may eventually draw the attention of a teacher or parent. A girl who engages in this same behavior, however, may simply be seen as bookish or quiet. Due to gender stereotypes like these, other tendencies and signs of autism may be missed as well.

Many women and girls report that they mask their symptoms from early ages. This tendency to camouflage may also contribute to this issue of underdiagnosis. Indeed, Lianne Holiday Willey's (1999) first autobiographical account is titled, *Pretending to be Normal*! Author Laura James (2018) wrote extensively about hiding autistic tendencies in her book, *Odd Girl Out:*

Whenever I tell anyone about my autism the response is always the same. They are surprised. They can't quite believe it. I seem too much like them and too little like the stereotypical view of autism they know. They think I can't be autistic because I am married. Because I work with words. Because I have successfully raised my children. Or because I don't say anything offensive in conversation. I am not what they expect. (p. 194)

Gender Diversity

Recent research suggests that autistic people are more likely than neurotypical people to be gender diverse, and that gender diverse people are more likely to have autism than cisgender people (Warrier et al., 2020). Interestingly, gender dysphoria—"the feeling of discomfort or distress that might occur in people whose gender identity differs from their sex assigned at birth or sex-related physical characteristics" (Mayo Clinic, n.d.)—also seems to be higher in autistic people (van der Miesen, 2016). The research in this area is fairly new, so the reason(s) for this finding is still unknown. One hypothesis, however, is that gender dysphoria is just as common in children and adolescents without autism, but is more commonly *expressed* in those on the spectrum because these individuals—who may be less concerned with social conventions—are not as likely to feel the need to suppress this identity (Saleh, 2021).

Evaluating the Evaluation

In a chapter focused on defining and understanding autism, it's certainly important to provide definitions and characteristics. I feel, however, that it is just as important to discuss underlying questions about the nature of those definitions and of the evaluation itself, such as: What do labels mean? How do our assessments help or hinder our work? and Who defines autism? These questions are explored in this section.

Learn About Labels

Diagnostic labels can be very helpful; they can provide students, families, educators, and researchers with a common language and framework and direct people to resources, funding, and services. In addition, labels can provide a starting point for educators in terms of making connections and having conversations; that is, teachers may be able to learn strategies from colleagues who have

expertise related to autism or from those who are autistic themselves. An overreliance on these labels, however, can serve as a barrier to understanding students as individuals and can lead teachers and others to believe that disability categories are static, objectively organized, and necessarily useful when, in fact, they are everchanging, subjective, and often seen as both helpful *and* limiting to both autistic people and others who use them to communicate about and understand human differences (Botha et al., 2021; Richards, 2016).

Because our understanding of autism and related labels is evolving constantly, it seems we can be sure of at least these three things: 1) we do not know enough about autism; we certainly do not know more than we do know (Anne Donnellan, personal communication, October 20, 2008); 2) we will have new definitions, terminology, understandings, and conceptual knowledge in the near future; and 3) we will eventually find that we were wrong about many things we thought we understood. If even one of these are true, it is important to be aware of cautions or problems associated with framing autism and labeling students.

Families who are desperate for answers and support may spend their child's early years moving from one professional to the next looking for clarification on their child's diagnosis: Is it autism? Is it a sensory need? Is it a learning difference? One mother asked me to observe her daughter and then proceeded to ask me if I thought she had autism or was, perhaps, just "on the spectrum." I was not even sure what the question meant, so I asked her to tell me what *she* thought about her daughter's label and identity. As we ended the conversation, I asked her only one question: "What would you do differently tomorrow if you called this autism versus some other related term?" In most cases, the answer is "nothing". If the child already has an IEP, the goals should not change and the supports should remain. This does *not* mean parents should avoid seeking answers or clarity on their child's needs or stop trying to better understand their challenges. There are, in fact, many reasons why families might want to get a second or even third opinion on diagnosis. I share this story only to underscore the role of teachers as it relates to a child's diagnosis. Even when a diagnosis is the access point to special education, a student's needs and individual profile should always drive supports, not their label.

Labels can be useful, but they do not provide educators with specific information about how or what to teach and they should not be used to group students for instruction or services. Labels are also not useful in indicating which milestones the student will reach or which abilities they will develop. Therefore, a label should never be seen as a limitation. Labels, instead, are best used to illuminate, guide, support, and potentially even inspire.

This mention of inspiration may be new to some. I include it because it is so important that educators understand that many individuals and families do not see an autism diagnosis as a tragedy or burden. Some, in fact, may wholeheartedly welcome this new identity. Many may feel a sense of camaraderie with others in the autism community. For example, I know of one student who was extremely excited to learn that he had the same diagnosis as his dad. Author, advocate, and parent Robin Chen recalled that the path to diagnosis was so overwhelming and unnecessarily dark at times that now—years later—she wishes her son's evaluation had ended in a joyful celebration complete with a banner, "Congratulations! It's autism" (personal communication, March 18, 2022).

Assess Assessments

Diagnosis and labeling often means that students will be assessed, observed, interviewed, and otherwise evaluated. Some of the tools and processes used for this purpose are innocuous, but others, like IQ testing, may be problematic for some students. The percentage of autistic students assumed to have intellectual disabilities is everchanging (Charman et al., 2010; Eveleth, 2011; Thurman, 2016), with researchers estimating that about 50% of individuals with autism have average or higher IQ (Katusic et al., 2021), and 31% of individuals on the spectrum have an intellectual disability (Autism Speaks, 2022).

The problem with this data and related reports in the last few decades is that characteristics of autism are often not taken into consideration as students are tested and results are interpreted. Although it may be true that many individuals on the spectrum have low measured IQs, it is reasonable to assume that those scores are, at best, questionable (Courscesne et al., 2015; Grondhuis

et al., 2018; Omahen, 2021). Sensory differences (e.g., auditory processing problems), communication challenges (e.g., language production struggles), motor planning issues, and even stress and anxiety (Donnellan et al., 2013) may affect how students engage with assessment tools and how they interact with the individual administering the instrument (Provost et al., 2007; Scheuffgen et al., 2000; Weimer et al., 2001; Wood & Happe, 2020).

The format of many tools and tests may also be a challenge for many children. Some instruments may simply not give autistic individuals the amount of time required to process, organize, reason, and perform challenging tasks. In addition, many of these tasks may be incompatible with the individual's needs or abilities. For instance, some learners have difficulty manipulating materials, responding to directions, or coordinating thoughts and actions. Autistic author, Ido Kedar, for instance, claims that his body has a mind of its own. Consider this excerpt from his 2012 autobiography wherein he describes his struggles with motor planning:

[T] oday my mom asked me to open my window while we were waiting in the parked car. It seems ridiculous to say that I know what a window is but my hand acted on its own repeatedly. I kept opening the car door instead. It was scary because I was forced to repeat this error. I mean that my mind knew window and my hand insisted on the door. It's worse than that though because then people deduce I don't know the difference between a window and a door. (pp. 70–71)

For students like Kedar, many assessment tasks will be difficult if not impossible. If asked to arrange blocks during an evaluation, a student may understand what is required but be unable to demonstrate that understanding due to movement problems or even anxiety. In this situation, the test will not reveal what the student knows; the evaluator will only learn that the student cannot arrange blocks on command.

Likewise, consider an assessment in which a student is asked to examine pictures of animals and choose "the one that lives in a barn." Again, if the child knows the answer is a cow but has no reliable pointing response or cannot process the question quickly enough, then they will fail that item. The problem with so many of these instruments is that they purport to assess student knowledge or skill, but many end up evaluating the severity or nature of the child's autism. In other words, many students taking these tests are being assessed not on the targeted abilities but on how efficiently their body works; how significant their movement, sensory, or communication problems are; and how well they deal with novel tasks and people.

When I was student teaching, I observed as one of my students struggled through such a testing session. Caleb, a nonspeaking teen with autism, cerebral palsy, and low vision, was a little restless when we arrived, but settled in quickly and appeared interested in the many materials displayed on the table in front of him. One instrument used during the evaluation was a nonverbal, multiple-choice test designed to assess an individual's receptive knowledge of vocabulary. The test required students to study four pictures at a time and answer increasingly difficult questions about the pictures. Early questions in the test simply required the students to identify a picture (e.g., "Which one is the tree?"). Subsequent questions tapped into higher order thinking and required the test taker to know about properties, qualities, or uses of the items and/or things pictured (e.g., "Which one eats grass?"). Caleb did not make it to the complex, higher order questions. He got the initial items wrong because he failed to point at anything, and he stabbed his finger at the wrong pictures in response to the next two questions.

Caleb wiggled in his seat and flapped his arms during the entire assessment. He tried to leave the room once and at least two times he placed his cheek against the testing materials and giggled. It was difficult to tell if he was uncomfortable, excited, confused, or frustrated. When the examiner asked him to try a few more items, he did so. Again, he put his cheek close to the picture page but seemed to tap almost randomly on the images. On the last test item, however, Caleb leaned back and grinned. The examiner had asked him to point to the light bulb. He was directed to choose from four pictures (e.g., horse, dollhouse, umbrella, light bulb). Caleb put his face close to the pictures one last time. Then he grabbed the table lamp in front of him and shook it wildly. The examiner took the lamp from Caleb and gently asked him to continue with the test. Again, she asked him, "Show me the light bulb," and again Caleb grabbed and shook the lamp.

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I suggested to the examiner that Caleb might be showing her the light bulb in the only way he could due to his motor planning problems and low vision. She agreed but explained that she could not know for sure. She did make some notes in on the evaluation sheet about the incident, but, in the end, Caleb's devastating testing report made it into his file, but his clever adaptation to the assessment did not.

As Caleb's story shows, assessment is problematic when the tools utilized do not take into account the unique needs of the student. This situation is exacerbated when the examiner does not know the child. Collaboration is critical in these instances. Consider the story of Wendy Robinson (2003), who took her son to the doctor's office for an evaluation only to be questioned and ultimately insulted by the professional assessing her son:

She asked me lots of questions and gave Grant simple tests to do. He failed miserably at most things. He was not in the mood today to perform in his usual contrary way. She asked me if he held his hands in the air when I removed his clothes before bath or bed.

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"Yes," I replied.
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"Are you sure?" she retorted. "I can't believe he does that." (p. 21)

Of course, many professionals are conscientious and well understand the need to work closely with trusted colleagues and families in these situations, but even the most sensitive educators should reflect on what types of values and beliefs they are bringing to an assessment. Everyone involved in the process should be committed to a team approach (i.e., student and family centered). Furthermore, students should be assessed using a range of tools, including observations across environments, work samples, interviews with family members, and, if possible, interviews with the student. Finally, if the assessment data does not appear to match your idea of what the student knows and can do, talk to your team and ask and answer the question, "What other strategies can we use to know this person, learn about their growth, and understand their abilities?"

Consider the Insider

Gail Gillingham (2000) challenged the ways in which most definitions of autism have been constructed in her book, *Autism: A New Understanding.* She contended that the lack of "direct exposure" is the primary flaw in most definitions. Gillingham compared the definition of depression with that of autism and pointed out that only the former seems to have been informed by the perspectives of those diagnosed:

When we look at the criteria for depression, we find it includes symptoms such as recurrent thoughts of death, markedly diminished interest or pleasure in all activities, and feelings of worthlessness. The criterion for Social Phobia includes the symptoms of a marked and persistent fear of social situations, the recognition that this fear is excessive and irrational and that exposure to the feared situation provokes anxiety. None of these symptoms can be determined without taking the actual experience of the person who is diagnosed into account. (p. 169)

Gillingham went on to explain that this honoring of the insider experience does not happen with autism. Instead, neurotypical professionals have relied on their own observations and interpretations:

Do we see an impairment in communication? Do we experience an impairment in social interaction? The repetitive and stereotypic behaviors are observed and measured directly from our viewpoint. No one has taken the time or effort to include anything from the actual experience of the autistics. I assume this is because we do not believe that they are capable of sharing anything useful. However, if the direct experience of those who are diagnosed with depression or social phobia is considered valuable information, why are we not accessing the same from those who have autism? I expect that this lack of input from direct experience invalidates the whole process of diagnosis . . . I am certain [the definition of autism] would not look the same if [autistic people] had the opportunity to add their comments. (p. 169)

Indeed, until the DSM-5-T was published in 2013, the definition of autism used in diagnosis appeared to ignore insider experience. It was behavioral. It was focused on what the person did versus on what they might have experienced (e.g., perceptual problems, anxiety). In general, this is still true, but the relatively recent addition of sensory needs does indicate a shift in thinking. Acknowledging sensory needs is, perhaps, the first step in inviting autistic people to share their experience of autism and to reconstruct a definition based not only on what is seen, but on lived experience.

This "outside" view of autism is problematic and it is tied to yet another concern with common definitions of autism—their focus on impairments alone. Although it may seem reasonable that a diagnostic manual focused on identifying disorders would highlight challenges, it is important to consider the role that competencies might play in the identification of autism. A diagnosis for most individuals is likely pursued due to needs (e.g., expressive problems, sensory sensitivity), but including certain strengths (e.g., exceptional memory, attention to detail) may give families (and individuals themselves) more data when deciding to pursue a diagnosis. This element of autism is given too little attention. I argue that exploring the strengths and abilities of autistic people can help be a tool in diagnosis and move the field of autism forward as well. In both research and practice, we should spend more time asking questions about abilities. We should be more curious about the strengths autistic people report and the ways in which they capitalize on those strengths.

A final criticism of diagnostic language is that it is filled with assumptions, and these assumptions can be incorrect or even damaging. For instance, for the purpose of diagnosis, behaviors are often described with phrases such as "prefers to" or "has unusual interest in" without specifying what behaviors or tendencies may lead to that impression and without exploring alternative explanations for those behaviors or tendencies. For instance, how can an observer (especially one who does not have an intimate knowledge of the child) know that they "prefer the company of adults" if the individual is not able to communicate this? A child assessed in this way may indeed prefer adults over children or there may be an alternative explanation. An autistic man I met told me that he was seen as someone who "preferred the company of adults" because he followed the recess monitor around on the playground. He shared that he actually did not prefer her company, but that he did like the fact that she walked in big loops around the perimeter of the blacktop and that was an activity he really enjoyed!

Teachers, especially those who conduct student evaluations, must always be aware of the impact of the language they use and the assumptions they make. Specifically, they must consider this: How might an "insider" see these behaviors, understand these observations, or describe this student?

Considering Common Characteristics of Autism

Although no two autistic students look, behave, communicate, or learn in the same way, individuals with this diagnosis do share some general characteristics. Some of the most significant characteristics are shared in this section, including movement differences, sensory differences, communication differences, social differences, learning differences, and interests and fascinations.

Movement Differences

Movement differences describe symptoms involving both excessive, atypical movement (Bell et al., 2019; Kapp et al., 2013; Ringman & Jankovic, 2000; Robledo et al., 2012; Sara, 2021) and the loss of typical movement. These difficulties may impede postures, actions, speech, thoughts, perceptions, emotions, and memories (Donnellan & Leary, 1995; Leary & Hill, 1996; Nayate et al., 2005). Individuals with movement differences may walk with an uneven gait, engage in excessive movements (e.g., rocking, hand flapping, pacing), produce speech that is unintentional, stutter, or struggle to make transitions from room to room or situation to situation.

Many autistic individuals experience these movement problems constantly. As my colleague Kathy Xenia Grant shares, even the smallest tasks can take effort by those on the spectrum:

We don't realize how complex movement is. How complex of a movement just picking up a pen is. What parts of the body it goes through and what parts of the brain. A lot of us on the spectrum [have these] motor planning problems. (Hussman et al., 2009)

Although many nonautistic people struggle to combine thoughts and movements, engage in excessive pencil tapping or nail biting, get lost in repetitive or obsessive thoughts, or hum the same tune repeatedly without realizing it, they are seldom significantly affected by these experiences. Some autistic people, however, find these behaviors to be pervasive and incredibly distracting and overwhelming at times. Some of these movements may be somewhat in the person's control but hard to navigate, and others may feel impossible to harness.

A movement difference can cause difficulties with dynamics and make starting, executing (e.g., controlling speed or rate), continuing, stopping, combining, or switching movements challenging. Disturbed movements may range from nearly imperceivable motions (quiet fidgeting) to behaviors affecting overall levels of activity (jumping up and down uncontrollably). Many individuals who experience movement disturbance also report differences in internal mental processes; they may have problems regulating perception, attention, consciousness, motivation, or emotion. For instance, in a documentary film titled *We Thought You'd Never Ask: Voices of People with Autism*, autistic researcher Sue Rubin shared that one of her primary challenges with autism is coping with feelings: "Autism is a way of life awash in emotions. Emotions rule me" (Husmann et al., 2009). In that same film, autistic advocate Stephen Hinkle shared that when he walks into a room, he looks around the space and pays attention to the elements of the environment (e.g., lights, furniture) before he begins to notice the people in it (Hussman et al., 2009).

Movement differences are frustrating for the people who experience them and confusing for those who observe them. According to Donnellan and Leary (1995), atypical movements often mask the abilities of individuals who exhibit them and may have an impact on a person's ability to communicate, relate to others, and demonstrate competence. They noted, "Delay in responding or [failure] to regulate movements may affect the ability to turn attention from one event to another in a timely fashion, or use conventional signs of communication" (p. 42). In many cases, these movement differences are assumed by observers to be symptoms of intellectual impairment when they are actually problems with the body.

Understanding and recognizing movement differences can help teachers better interpret the meaning (or lack of meaning) in a particular behavior. For instance, a teacher who is unaware of a learner's movement problems might assume that a student who stands up several times during a classroom discussion is unable to focus on the lesson or uninterested in the material, when, in fact, these behaviors may indicate very little, if anything, in terms of the individual's level of attention and ability to learn.

From the Experts Experiencing Movement Differences

Consider how some autistic individuals describe their movement differences:

I never really know when sounds are coming out of my mouth or when my arms need to move or when my legs need to run and jump. I also have a hard time controlling my thoughts when someone is not helping me focus. You see my mind is very active and thoughts jump around like popcorn being popped. I have very interesting thoughts. It's just that they keep firing off so fast that it's hard to stop them unless someone helps to focus my attention on something. You can imagine how hard it is to get anything done with a roller coaster mind without any clear destination. My eyes are unable to move up and down and left to right at will without me moving my head in the directions I'm facing. I can see things really well from the corner of my eyes. When I look at someone facing me sometimes. This makes it hard for people to know whether I'm paying attention. (Fihe, 2000, p. 1)

I tried to learn a very simple line dance. I could not learn my footsteps and my hand movements at the same time. I had to teach my feet how to do it then stand still. I had to hold on to a rail, teach my feet their steps then lean against the wall with my feet out balancing me and learn my arm steps. Then hold on to the bar and learn my torso steps and then from there you learn what to do with the hips. Slowly, I turn the music on slow and I very, very, very slowly start the feet and very slowly add the hands then very, very slowly add the torso, etc. Everything has to be thought out, that is what is so annoying. There are just a very few things that I do two things at the same time without thinking them through as I am going. (Robledo et al., 2012, p. 6)

How to conduct myself when the body is constantly trying to find some stability? By this I mean to say that some times I felt that my body was made of just my head while sometimes I felt that it was made of just my legs. It was very difficult to feel the complete body when I was not doing anything. (Mukhopadhyay, 2000, p. 73)

At school I was more direct in how I expressed my irritation and scorn, getting flushed, giggling uncontrollably, running around the room and biting my hand. (Blackman, 2001, p. 127)

Stereotypical movements aren't things I decide to do for a reason; they're things that happen by themselves when I'm not paying attention to my body. (Cessaroni & Garber, as cited in Donnellan & Leary, 1995, p. 53)

Constantly asking questions was another of my annoying fixations, and I'd ask the same question and wait with pleasure for the same answer—over and over again. If a particular topic intrigued me, I zeroed in on that subject and talked it into the ground. (Grandin, 1996a, p. 35)

Sometimes I am just not able to contain my actions and myself. Ninety percent of an autistic person's efforts while in public are spent trying to avoid inappropriate behaviors that "normal" people seem to be able to easily suppress. One place where I had a terrible time trying to sit still and not make noise was in the small theater watching the play *The Diviners*.

I didn't have a terrible time at the play, quite the contrary. In fact, I loved this play. Deep into the drama, I relaxed my guard and was soon a noisy, rocking-back-and-forth-in-my-seat spectator. Good things don't often cause this reaction, so we might say that the lan Weatherbee behavior-o-meter registered a four-star reading for *The Diviners* and its excellent cast. (Weatherbee, 1999, p. 2)

But I am not hurting anyone when I scream and I need to do it so much to get my balance perhaps one day I won't need it but now I am sure it is still important. (Sellin, 1995, p. 216)

Sensory Differences

Autistic people experience a range of sensory problems (Perez Repetto et al., 2017). Students may exhibit hypo- or hyperresponses to visual, auditory, olfactory, gustatory, tactile, vestibular, and proprioceptive sensitivities; all of these can have an impact on a student's classroom performance and behavior (Kern et al., 2006; Myles et al., 2004; Yack et al., 2015). Fluorescent or intense lighting, food with unappealing textures or tastes, speech that is too loud or too fast, unexpected or painful sounds, perfumes or strong odors, chaotic visual fields, rooms that are too warm or too cool, and scratchy clothing are among the sensory "violations" that people on the spectrum report (Howe & Stagg, 2016; Myles et al., 2000; Perez Repetto et al., 2017; Yack et al., 2017). To make matters more complicated, responses to sensory stimuli will often change throughout the day depending on each individual's "sensory threshold" (Aquilla et al., 2015) or level of tolerance. Therefore, it can be hard to predict what types of difficulties a learner may have on any given day with any particular sensory issue.

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When sensory issues become overwhelming, the autistic person may experience sensory overload. Meredith Lime (McGlensy, 2016), an autistic woman, described what this feels like for her:

66 Do you remember the movie Bruce Almighty? He was receiving prayer requests by hearing them in his head as they occurred, hundreds at a time. They became jumbled, and he became frustrated and couldn't make sense of any of them. Sensory overload is like that. Everything is coming at me at once, but it seems I'm the only one noticing. I can hear my heartbeat, I can feel the heat of the lamps, I can't function. I'm frozen, stuck. It usually takes a shock to get me back from this, like a touch if I'm not being touched, or a change of environment or cold water on my skin.

Every student will have a different sensory profile. Although Lime's experiences may not be unusual for an autistic person, this specific collection of concerns is likely unique to her. Many autistic students, however, will experience some sensitivities be they tactile, auditory, visual, or olfactory.

Tactile Sensitivity: One of my students could not tolerate being touched in a gentle way. If a classmate brushed his hand or tried to guide him somewhere by lightly grasping his shoulder, then he screamed as if in pain. If they gave him a bear hug or shook his hand firmly, then he appeared unaffected. This is just one example of how tactile sensitivity can affect autistic students. Tactile sensitivities may occur across activities and environments (Mikkelsen et al., 2018; Schaffler et al., 2019) and can affect the way students use space (e.g., avoiding touching or working near others), work with supplies (e.g., avoiding or preferring certain materials), and interact with others (e.g., craving or avoiding hugs).

Auditory Sensitivity: Many autistic people experience auditory processing problems. Students may be more sensitive to sound than their peers. Some may be bothered by sounds that teachers cannot even detect. Tyler Fihe (2000), an autistic teen, reported that he often hears things other cannot:

GG For example, I can be in one room of the house and hear what my mother is saying on the telephone even when she has the door shut. There are also certain sounds that are painful to listen to like the microwave, the telephone ring, lawnmowers, leaf blowers, the blender, babies crying, vacuum cleaners, and my mom's VW Vanagon when it just starts up. (p. 1)

As Fihe (2000) pointed out, a range of noises and sounds may cause autistic people distress, including those that may seem benign to most. For instance, a student might be completely distressed by the sound of an eraser rubbing on paper or frightened by the hissing of a radiator. Many autistic people also have trouble understanding conversation or verbal directions. This may be especially true during sensory overload. As one autistic woman shared, "I hear everything [at these times, but it's not speech], just many sounds, unfiltered and loud" (McGlensy, 2016).

Visual Sensitivity: Students with autism may be sensitive to certain types of light, colors, or patterns. This sensitivity may not only have a negative impact on the person's sensory system but can also cause them to become fearful or anxious:

66 It may be because things that I see do not always make the right impression that I am frightened of so many things that can be seen: people, particularly their faces, very bright lights, crowds, things moving suddenly. Large machines and buildings that are unfamiliar, unfamiliar places, my own shadow, the dark, bridges, rivers, canals, streams, and the sea. (Jolliffe et al., as cited in Attwood, 2007, p. 285)

Conduct informal observations to assess your own student's sensitivity in this area. If a student seems bothered by things they see in the classroom (e.g., a certain poster, a bulletin board), changes may need to be implemented. Even some colors may bother a student's sensory system, so request neutrals when it is time to paint your classroom (Altenmüller-Lewis, 2017).

Olfactory Sensitivity: Autistic people may also have a heightened or otherwise different sense of smell (Ashwin et al., 2014). An individual may find some smells overarousing and unbearable and others pleasant, helpful, or calming. For instance, one of my former students avoided any teacher

who wore perfume but loved to smell the hair of a fellow student who used strawberry shampoo. Students with olfactory sensitivity may struggle with any number of odors in the school, including art or craft supplies, class pets, cleaning products, food, and science chemicals. (See Chapter 5 for more information on supporting students with sensory differences.)

Communication Differences

Many autistic individuals have communication differences that affect speech and language (Ganz & Simpson, 2018; Scholten et al., 2021); some use few or no spoken words. For students who do speak, their speech may have unusual qualities. For instance, a student may have atypical speech intonation or use repetitive speech (echoing the words of others). Furthermore, conventional conversational timing and rhythm may be difficult for someone with autism to learn or use. Students might also struggle with using language. Some may be confused by the rules of conversation. Others may find figurative language hard to decipher.

Students with autism may have difficulties with expressive or receptive communication (i.e., they may have trouble sharing thoughts and ideas, they may struggle to understand what they hear or see). Many students experience difficulties with both receptive and expressive communication.

Supporting students with communication needs is a two-way street. Students will certainly need strategies, feedback, guidance, and encouragement to learn skills and succeed in the class-room. True support, however, also means being willing to learn from students and accepting that some communication differences may be strong preferences that can and should be honored. For instance, some students do not like small talk and may be a bit direct in their communication. Help in that instance might mean giving the learner feedback that they have a very direct style of communication, teaching them some strategies to soften that style, but also helping them to teach peers about how to engage with someone who is more direct in conversations.

Using AAC is another way to support students with communication challenges. Autistic individuals are increasingly finding communication success through the use of various technologies, including devices and apps (see Beukelman & Light, 2020; Bondy & Frost, 2002; Collette et al., 2019; Crossley, 1997; Douglas & Gerde, 2019; Gilpeer & Grodin, 2021; Higashida, 2017; Mukhopad-hyay, 2003; Pena, 2019; Stoner et al., 2006; Thunberg et al., 2009). These tools are not only giving students access to words, but in many cases are also changing the ways educators, families, and researchers think about the abilities and potential of autistic people. (See Chapter 7 for more information on supporting students with communication differences.)

Social Differences

A common stereotype is that autistic students are not interested in social relationships. John Elder Robison (2007), the author of the bestselling autobiography, *Look Me in the Eye*, explained that in his case, nothing could have been further from the truth:

66 Many descriptions of autism and Asperger's describe people like me as "not wanting to connect with others" or "preferring to play alone." I can't speak for other kids but I'd like to be very clear about my own feelings. I did not ever want to be alone. And all of those child psychologists who said, "John prefers to play by himself," were dead wrong. I played by myself because I was a failure at playing with others. I was alone as a result of my own limitations, and being alone was one of the bitterest disappointments of my young life. (p. 211)

Daniel Tammet (2006) shared a similar sentiment about social concerns:

66 People with [autism] do want to make friends but find it very difficult to do so. The keen sense of isolation is something I felt very deeply and was very painful for me. (p. 78)

Stories such as these are more common than some might believe. The characterization of the person on the spectrum as aloof or disconnected is as pervasive as it is potentially damaging. Although some autistic people do report that they need time alone or find some social situations challenging, some of these same individuals also claim that they crave social interaction and friendship. It is possible for a person with autism to both struggle with and want relationships.

Some autistic individuals claim that being with people is not challenging, but it is the social settings themselves that make being with others difficult. For instance, my friend, Thea, values the one-to-one relationships she has with her sisters, nieces, and nephews but cannot tolerate family events such as weddings, birthdays, and graduation parties because of the noise, the bright lights, and the confusion of the games, dances, and rituals that go with those celebrations.

Others find social situations difficult because they struggle with the skills commonly associated with successful social interactions (Prizant, 2015). For instance, autistic individuals may not be very good at reading subtle social signals. If a person begins putting on their jacket, then most people read this as a sign that that individual is getting ready to end the conversation and leave that environment. That signal might be missed by some autistic individuals, and they may not stop chatting, say "goodbye," or initiate the close of the conversation in the same way a neurotypical person might.

Understanding pragmatics or the use of language in a social context is another common challenge for individuals on the spectrum. John Elder Robison (2007), the man who lamented about the social perceptions others had of him earlier in this section, shared his many social struggles throughout his book. One that he explained in great detail is his inability to master small talk and ask the types of polite questions acquaintances sometimes exchange:

66 Normal people seem to learn certain stock questions and utter them to fill a conversational void. For example, when meeting someone they have not seen in a while, they say things like:

"How's your wife?"

"How's your son?"

"You're looking good-did you lose weight?"

Normal people will emit statements like this in the absence of any provocation, or any visual indication that there may have been a change in the wife or son or the weight. Some people I've observed appear to have dozens of these stock questions at their command and I have never been able to figure out how they choose a particular phrase for emission at any given moment. (pp. 192–193)

Other challenges that autistic people may have with pragmatics include difficulty shifting topics and initiating and repairing conversations, providing the appropriate level of detail or information during a conversation, and reacting to or integrating the comments or reactions of conversation partners when speaking in a group.

It must be noted, however, that misunderstandings and social confusion are not only problems of those on the spectrum. Neurotypical conversation partners, or individuals who are not on the autism spectrum, do not always realize how confusing and arbitrary social rules sometimes appear and may be unaware of how helpful it can be to clarify norms in conversation or social situations. In addition, some autistic students may struggle socially because those around them do not understand their attempts to be social or interact. For example, one of my former students, Donna, often ripped paper from her notebook, crumpled it into a ball, and tossed it at her classmates. Students reprimanded Donna for this behavior and repeatedly told her, "Donna, don't throw garbage at your friends." When I told Donna's mother about the behavior, however, she gasped and then laughed. She then explained that Donna was imitating her brothers; when her older brothers wanted to play with her, they crumpled paper into little balls and pretended to shoot baskets through hoops they made with their outstretched arms. In Donna's house, a fun social interaction could be initiated by throwing paper in someone's direction; the appropriate response, of course, was to arc your arms to make a "basket" for the shooter. From Donna's perspective, she was behaving perfectly appropriately; it was her classmates who lacked social awareness.

Lucy Blackman (2001), an autistic woman, emphasized the importance of realizing the different ways that students initiate social contact and interaction:

For me, successful "social" contact depended on someone else interpreting my own signals. Some of my attempts at communication were fairly conventional, as when I put my arms up towards a person with my hands stretched up because I desperately needed to be picked up or lifted over an obstacle. However [mom] noted that if I turned my hands outward when I put my

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arms up to her, I was asking for a boost for a somersault, rather than some help in climbing up. If she interpreted wrongly, things could get very noisy. (p. 11)

Blackman (2001) illustrated the need to exercise caution when interpreting any behavior. In her case, what may have seemed like a simple request to be moved or helped actually meant, "Play with me!" a sweet social request that could easily be missed by those who did not intimately know her. (See Chapter 10 for more information on supporting students with social differences.)

Learning Differences

In addition to having communication, sensory, and movement differences, some autistic people also report learning differences or difficulties. For example, Donna Williams (1996), an autistic memoirist, has written extensively about her many types of processing difficulties. She referred to one category as "sorry, wrong address" or "misfires":

66 Messages can be sorted inefficiently so that they are related badly. This is like putting a call through to the wrong number or the next-door-neighbor's house instead of your house. These are what I call "misfires." Some examples of these in my own life have been where I've

come up with words or names that have a similar shape, pattern or rhythm to one I am trying to recall without being similar in meaning. I've had this trouble with names such as Margaret and Elizabeth because they seem to have the same feel and seem similar to me.

In the same way, I've said things like "I want my shoes" when I meant "I want my jacket" and been surprised to get things I apparently asked for. (p. 89)

Sue Rubin (1998), an autistic researcher, reported that she has significant problems with memory:

66 I have a deficit in my thinking and I don't know if it is common in autism or is just unique to me. When I remember events, I can't tell if they really happened or I imagined them. I can actually picture events in my mind and I am sure they are real until someone points out that they couldn't have happened. Awash in embarrassment, I realize that I imagined the event. I even worry about imagined events that I think really happened. Waking nightmares may be a good description. Lasting problems can result from this. The problem with my memory does not affect my schoolwork. I learn what is in my books, what the professor says, and what everyone says in class. I admit I still have problems with assignments. I need someone to write them down for me because I cannot recall them. Assume my forgetting assignments is much worse than normal people's forgetting. (p. 3)

Many documented learning problems (e.g., executive functioning challenges, language processing problems) in autism are similar to the types of struggles reported by individuals with learning disabilities (Bailey, 2020; Gilroy & Miles, 1996; Kurtz, 2006; Mooney & Cole, 2000; Smith & Strick, 1997). In other words, teachers may assume that a student does not or cannot give a correct answer or respond to a direction because they are incapable of understanding the task. In many instances, however, that student may be struggling to respond or perform in an expected way because of the way in which the information is presented or processed. Strategies that may work in this situation include increasing the use of visuals, chunking the task or request down into manageable segments, or modeling how to respond or participate.

Special Interests or Fascinations

Many autistic people have a deep interest in one or a variety of topics (Fields-Meyer, 2011; Fournier, 2016; Suskind, 2016; Winter-Messiers, 2007; Wood, 2019). Some interests are commonly seen across individuals with autism (e.g., video games, weather, maps); others seem more unique to an individual person (Kluth & Schwarz, 2008; Winter-Meissiers, 2007; Wood, 2019). For instance, Sean Barron, an autistic man, once had a great interest in the number 24. At another point in his life, he became fascinated by dead-end streets (Barron & Barron, 1992). Phil Dougherty (2006) shared

that his daughter, Jenny, has been, at different times, fascinated with slugs, fire alarms, and recycling symbols. Tom Fields-Meyer (2011) reported that his son, Ezra, cycled through many "powerful and all-consuming" loves ranging from the Muppets to Gumby to movie release dates.

Unfortunately, these special "loves" that students bring to schools are not always celebrated or even tolerated. Many a meeting has been planned and many a behavior program has been written to squelch a student's fascination. This tendency should be scrutinized for many reasons but primarily because special interests can be valuable tools used to support students on the spectrum. Grove and colleagues (2018) found that special interests were positively associated with feelings of well-being in autistic adults, Koenig and Williams (2017) reported that "favorites" were often used to explore possible jobs and careers, and Gunn and Delafield-Butt (2016) found that fascinations could be incredible tools for learning and support. For instance, a second-grade teacher in their study gave a student some *Thomas the Tank Engine* books, and the child's reading comprehension improved from a first- to a mid-second-grade level in just a few months.

For these reasons and others, Willey (2001) cautioned that it can be dangerous for nonautistic people to pass judgment about someone else's special interests. In fact, she noted, in many ways and in many circles, having intense interests is considered positive and even admirable.

At the base I have to wonder, are we so very different from marathon athletes, corporate presidents, bird watchers, or new parents counting every breath their newborn takes? It seems lots of people, NT [neurotypical] or otherwise, have an obsession of sorts. In my mind, that reality rests as a good one, for obsessions in and out of themselves are not bad habits. There is much good about them. Obsessions take focus and tenacious study. They are the stuff greatness needs. I have to believe the best of the remarkable—the artists, musicians, philosophers, scientists, writers, researchers and athletes—had to obsess on their chosen fields or they would never have become great. (p. 122)

Luke Jackson (2002) observed that it seems okay for people without disability or autism labels to have these interests in our society but not those with these labels and identities:

L I have a question for teenagers here.

Q: When is an obsession not an obsession? A: When it is about football. How unfair is that? It seems that our society fully accepts the fact that a lot of men and boys "eat, sleep, and breathe" football, and people seem to think that if someone doesn't, then they are not fully male. Stupid! (p. 47)

Additionally, he noted that this inconsistency seems to be rooted in an intolerance for uniqueness:

66 I am sure if a parent went to a doctor and said that their teenage boy wouldn't shut up about football, they would laugh and tell them that it was perfectly normal. It seems as if we all have to be the same. Why can no one see that the world just isn't like that? I would like everyone to talk about computers all day actually, but I don't expect them to and people soon tell me to shut up. (pp. 47–48)

To access the benefits detailed in research on special interests and to honor the viewpoints of autistic people like Willey (2001) and Jackson (2002), teachers should, when possible, integrate them into curriculum, instruction, and daily routines. There is so much potential for learning and engagement with this strategy (Winter-Messiers, 2007; Wood, 2019). A lover of laundry machines could be given a washing machine user guide during a literacy lesson. Laundry terms could be integrated into math problems (e.g., "If one rinse cycle is 15 minutes and you cut it short by six minutes, how long did you rinse your shirts?"). Challenging vocabulary could be assigned (e.g., agitate). An independent study on the history of the washing machine could be suggested.

Teachers can also allow a student with a specific fascination the time and space to integrate it into the school day on their own if it's not disrupting the student's education or hurting them. For instance, a teacher asked me what to do about a student who often signed his papers "Mr. Rogers" because he was a big fan of the children's entertainer and of the program, *Mr. Rogers' Neighborhood.*

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We determined that this was both pleasing and comforting to the student and that it was not getting in the way of his learning. She ended up giving him a simple guideline to follow, which was, "Use your real name for tests, quizzes, attendance, and school forms so you are given credit for your work and so the school gets key information it needs from you." He was easily able to follow that rule and was allowed to continue to use his alter ego's name on most days and on most of his work until his interest changed a year later to pop art.

"Leaning in" to fascinations is undoubtedly a powerful teaching strategy. At times, however, a different approach may be necessary. Some students want or need help restricting behaviors or time spent with fascinations, especially if they are dangerous or inappropriate for school. The plan that is designed for this purpose should always be respectful and, whenever possible, developed in collaboration with the student.

Willey (2001) suggested talking to the autistic student about the "good and bad parts of obsessing" and introducing parameters. In her book on parenting and autism, she shared a story of how she helped her daughter learn how to live in concert with her interests:

Slowly, patiently, with tiny steps we are trying to help her find the good and the bad parts of obsessing. "It is good to play with your monkey collection when you feel badly about something that happened at school," we tell her. "Of course you can buy that book about monkeys because you worked hard to control your temper this whole week," we will say. "No, you cannot sort your monkeys right now, not until your homework is finished," we remind her. In time, she will do these things for herself. In time, she will know on her own how to share her life with her obsession. (p. 125)

If the student is not interested in moving away from their interests, then the teacher should proceed with caution (see Chapter 11 for more information on supporting students with special interests). In many cases, some people in the student's life may want an interest to recede when the student does not. Eugene Marcus (2002), a writer, teacher, and autistic advocate, has indicated that fascinations and interests often serve important purposes in the lives of those on the spectrum. He has stressed that individuals should be allowed to assess and control their own interests, compulsions, or fascinations, when possible:

66 My own view is that my life is enriched [by my habits]...nobody else forces me to be compulsive, or even gives me permission to be compulsive.

My wish is to one day be free of my compulsions, but not any day soon. [Through my compulsion], I have learned things I never would have through silent cooperation. I have tested the limits of my real and unreal friends (even those people who wanted to be my friends, but only when I was play-acting a role—not being myself). My compulsive behavior has allowed me to set my own agenda in situations where the most I could have hoped for was "eats and treats." My compulsive behavior is a long-playing defense against well meaning people who cannot guess what I really am thinking of or wishing for. How can I be a non-compulsive person but also not compulsively agreeable? Because I can see that in compulsive agreeing is a big risk of losing my path and my dreams. (p. 8)

Summary

Until the movie *Rain Man* (Johnson & Levinson, 1988) was released, few people knew what autism was and fewer still knew a person with that diagnosis. Although the popular motion picture gave the average person a glimpse into this little-understood diagnosis, it also provided them with a range of stereotypes about autism. In the wake of the film, many viewers came to believe that every autistic person could recite the phone book, count cards, and memorize the TV guide.

Today, more than three decades after the movie's debut, the general public's awareness of the autism spectrum has greatly increased and educators understand more about autism than they ever have before because of deinstitutionalization; the growth of community living and employment for people with disabilities; the proliferation of advocacy groups both nationally and in local communities; more accurate and varied accounts of autism in biographies, autobiographies, magazines,

motion pictures, and television; and more autistic people taking on teaching, research, and advocacy roles in schools and nonprofits. As I shared in the introduction to this chapter, many educators are also learning about autism from their experiences teaching in inclusive schools and specifically from their students.

This chapter can certainly serve as a primer, but the best way to find success with any autistic student is to get to know that individual and welcome them into your classroom. In her autobiography, *Through the Eyes of Aliens: A Book About Autistic People* Jasmine Lee O'Neill (1999), shared why it is so important to do so:

Many autistic people affectionately, humorously refer to themselves as aliens. They feel displaced on a vast planet, which has a code of life, and understanding they can't ever quite subscribe to. If they are welcomed, however, and cherished as the individuals they are, then there wouldn't be as much dissension on both sides. Aliens can become more comfortable and less paralyzed in fear, while still remaining who they are. Their essence stays the same. Then they don't have to despise their alien status, as if it were forced upon them. Instead, they can enjoy their uniqueness, just as others enjoy theirs. (p. 125)

FOR DISCUSSION

- What did you know about autism before reading this chapter? What did you learn after reading this chapter?
- What are some of the benefits of understanding definitions and descriptions of autism from autistic people? In what ways are these definitions and descriptions illuminating? Surprising? Useful?
- How can understanding gender differences in autism help classroom teachers better support students?
- There are many challenges related to assessing the abilities of students on the autism spectrum. Have you ever struggled to assess the abilities and skills of a student like Caleb? How might an awareness of the problems outlined in this chapter change our evaluation practices?
- Movement differences is a characteristic of autism that may be new to some educators. Have you seen evidence of movement differences in any of your students? If so, how do these differences impact their learning or schooling?

FOR MORE ANSWERS AND INFORMATION

Books

- Attwood, T. (2015). The Complete Guide to Asperger's Syndrome. Jessica Kingsley Publishers.
- Biklen, D. (2005). Autism and the Myth of the Person Alone. NYU Press.
- Collins, P. (2005). Not Even Wrong: A Father's Journey into the Lost History of Autism. Bloomsbury.
- Donnellan, A., & Leary, M. (2012). Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating People With Communication and Behavior Challenges. DRI Press.

- Endow, J. (2019). Autistically Thriving: Reading Comprehension, Conversational Engagement, and Living a Self-Determined Life Based on Autistic Neurology. Judy Endow.
- Grandin, T. (2021). *Navigating Autism: 9 Mindsets for Helping Kids on the Spectrum*. W. W. Norton & Company.
- Kluth, P., & Shouse, J. (2009). The Autism Checklist. Jossey-Bass.
- Prizant, B. (with Fields-Meyer, T.). (2022). Uniquely Human: A Different Way of Seeing Autism. Simon & Schuster.
- Shore, S. (Ed.). (2004). Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum. Jessica Kingsley Publishers.

Websites



Autism National Committee: autcom.org

This advocacy organization is dedicated to "social justice for all citizens with autism" and works to protect the human and civil rights of autistic people.

Autistic Self Advocacy Network: autisticadvocacy.org

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement. The goal is to create "a world in which autistic people enjoy equal access, rights, and opportunities."

Autism Society: autism-society.org

The goal of the Autism Society is to increase awareness about the common issues faced by autistic people. Check out their many local chapters to find additional resources.

Global and Regional Asperger Syndrome Partnership: grasp.org

The mission of the Global and Regional Asperger Syndrome Partnership is to improve the lives of those on the spectrum; the site is a great resource for teen students on the spectrum as well as for teachers.

Thinking Person's Guide to Autism: thinkingautismguide.com

The Thinking Person's Guide to Autism is a project of the Myers-Rosa Foundation, which is dedicated to autism advocacy, education, and community support. The aim of the site is to create "a reliable, centralized, and accessible resource by writing, curating, and sharing original autism news and articles."

"The practical helpfulness...is quite evident. What is most helpful is something Kluth has always done well—understanding and starting with who autistic people are and how that impacts all of everything for autistic people. Because of this focus throughout, Kluth leads us all down the path so that a truly inclusive experience—where everyone involved thrives—can be had by all."

-Judy Endow, LCSW, author, international speaker, and first autistic person to receive the Autism Society of America's Cathy Pratt Professional of the Year Award

"Dr. Kluth has done it again!...Practical and immediately useful information and resources abound in a book that celebrates the assets and strengths of children with autism." —Jennifer A. Kurth, Ph.D., The University of Kansas

"Dr. Paula Kluth has the gift to think out of the box and urges educators, clinicians, and families to push back against 'deficit-checklist' approaches to celebrate the great potential for every student... Paula once again is energizing the paradigm shift that enhances the important work of professionals and improves quality for families and so many children."

-Barry M. Prizant, Ph.D., CCC-SLP, University of Rhode Island, author of Uniquely Human: A Different Way of Seeing Autism

ne of the most popular, practical, and trusted books on inclusive education, this bestselling guide is now in a fully updated third edition-perfect for K-12 educators teaching the growing number of students on the autism spectrum. Created by Paula Kluth, a former teacher and celebrated inclusion expert who works with teachers and families nationwide, this book gives educators sensitive new ways to see autistic students and instantly useful strategies for teaching and welcoming them in general education classrooms. Pre- and in-service educators will get real-world guidance on supporting autistic students-from the big picture of planning and collaboration to the practical details of classroom arrangement, teaching strategies, and positive behavior supports. With a clear focus on the strengths, gifts, and perspectives of autistic learners, this book is the ultimate guide to meeting each student's individual needs in the inclusive classroom.

What's New

- All chapters updated to reflect the latest research and recommended practices
- More insights from autistic people and their family members
- Engaging new features: learning objectives, bulleted organizers, and discussion questions
- More online forms, student worksheets, planning tools, activities, and checklists
- More graphics, photos, and artwork that illustrate and reinforce key points

ABOUT THE AUTHOR: **Paula Kluth, Ph.D. (she/her),** is a highly acclaimed consultant, author, advocate, and independent scholar who works with teachers and families to provide inclusive opportunities for students with disabilities and create more responsive and engaging schooling experiences for all learners. She has served as a K–12 classroom teacher, co-teacher, inclusion facilitator, and university professor. Learn more about Paula's work on her website: www.inclusionrules.com.

