

LIBRARY PROGRAMMING

for **AUTISTIC CHILDREN** *and* **TEENS**

SECOND EDITION

Amelia Anderson

Foreword by Barbara Klipper

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AMELIA ANDERSON, PHD, is an assistant professor of library and information studies at Old Dominion University who has extensive experience on the topic of autism and libraries through her work as a public librarian, library researcher, and educator. She has worked to develop training for librarians to better understand and serve their users on the autism spectrum through two IMLS-funded initiatives, Project PALS and Project A + . Through original research and partnerships with autism self-advocates, Anderson studies and shares best practices and trends at the intersection of autism and libraries, and has presented her work at conferences ranging from local to international audiences.

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Foreword

by Barbara Klipper

IN 2011, NOT LONG AFTER STARTING A GRANT-FUNDED SENSORY STORY-time at the Ferguson Library in Stamford, Connecticut, I organized and presented at a session called “Sensory Storytime: Preschool Programming That Makes Sense for Children with Autism” at that year’s ALA Annual Conference. At the time, this type of program was almost unheard-of, and my goal was to bring it to the attention of youth services librarians around the country.

The session was well-attended and appeared to be well-received, and I was relieved when it was over. Then the unbelievable happened. A woman walked up to me brandishing a business card. She asked if I had ever thought about writing a book on the subject. I was floored. I had published a number of articles but never thought of writing a book, but she had planted a seed. Soon after, I developed and submitted a proposal to ALA Editions, which led to my 2014 book, *Programming for Children and Teens with Autism Spectrum Disorder*.

The book got good reviews, including a star in *School Library Journal*, and after its publication I gave conference presentations, webinars, and library system trainings. I became involved with Targeting Autism, an initiative of the Illinois State Library, and I have been presenting at its national forums and serving on its advisory board. I started a grant called “Autism Welcome Here: Library Programs, Services and More,” which awards \$5,000 in total annually to initiatives that make libraries more accessible to autistic people. The grant committee I put together consisted of me, another youth services librarian, a library director, the creator of Targeting Autism, the director of an autism agency, and an autistic self-advocate. All of these were people I met through Targeting Autism.

Over the five-year history of the grant to date, I have seen a marked change in the sophistication and creativity of the applications. The incidence of autism has increased over that period of time, but so has the response of the library world, and especially youth services, to it.

During this same period, equity, diversity, and inclusion (EDI) in both libraries and its own organization became a goal of the American Library Association.

This goal was championed by Loida Garcia-Febo during her ALA presidency, and it came to the fore as librarians educated themselves about systemic racism, and the Black Lives Matter movement spread across the country. While EDI is most often associated with racial injustice and underrepresentation, it applies equally to people with disabilities, who also face rampant discrimination in our society and underrepresentation in our literature and libraries.

Since writing my 2014 book, I have learned a lot through the Targeting Autism forums, my own understanding of EDI, and my own reading and increased social and political awareness. I came to realize that there were things I would do differently now and that a major deficiency of the book was its lack of representation, since I had parents and professionals speak to the experience of autism rather than autistic people, for whom this was their lived experience.

Since I wrote the book, the autism world has also evolved. Previously accepted but problematic terminology has been largely abandoned, and the neurodiversity movement has grown along with the adoption of the social model of disability, which addresses the need to reduce barriers for autistic people so they can participate freely in society. It became clear to me, given the changes in the country, in libraries, and in myself, that a new edition of the book was needed.

However, even as more library programs and services became available for autistic young people, I became deeply concerned about what happens to them and to those with other disabilities as they age out of the educational system. I now wanted to spend my time shining a light on the needs of these adults and showing librarians what they could do to help fill the gap in services and programming for them. My mentor, collaborator, and friend Carrie Banks and I decided to write a book similar to my book about programming for autistic youth, but this one would be about adults, and so we pitched it to ALA Editions. The problem was that I couldn't both update the youth programming book and write the adult programming book, nor did I want to, much as I desired to see both happen.

Then I thought of Dr. Amelia Anderson, a knowledgeable and accomplished academic whose work focuses on the intersection of autism and libraries. I had met Dr. Anderson at the Targeting Autism forums, and I knew she would be the perfect person to research and write a new, updated edition of my 2014 book. And I was so right. I'm extremely grateful that when I approached Dr. Anderson to ask her if she would consider the project, she enthusiastically agreed on the spot. What you hold in your hands is the result, and Dr. Anderson has done me proud, updating the book in many ways and centering the voices of autism self-advocates in the conversation, where they are meant to be.

I hope that those of you who found my 2014 book useful are as pleased with this new edition as I am. And because I could trust Dr. Anderson with it, Carrie Banks and I had the opportunity to write our companion book, *Programming for Adults with Developmental Disabilities*. I hope your library will get and use that volume as well.

Acknowledgments

I AM ETERNALLY GRATEFUL TO THE COMMUNITY OF LIBRARIANS WHO shared program examples and best practices with me as I researched this book. In particular, the following librarians offered incredible insight.

Thanks to Heather Baucum, an incredibly dynamic school librarian in Virginia, for sharing about the incredible systems she has in place to support autistic students. Renee Grassi is a leader in inclusive library services, and the innovative work she has done contributed to this book significantly. Jen Taggart provided invaluable information about best practices for storytimes, as well as information about providing those services virtually. Erin Lovelace and Julia Frederick generously shared storytime examples, and Marie Plug shared examples from her library's blog. Thank you to Shelley Harris and Carrie Banks for sharing information about inclusive gardening and more. School librarians Katie Kier and Rachel LeClair generously shared examples of how they conduct successful programs. Along with a great team, Dianne Aimone conducted a series of successful programs with an "Autism Welcome Here" grant, and shared the results and program plans for inclusion in this book. I appreciate the time Ryan Moniz spent sharing with me about the teen and young adult programs he put into place. Anne Leon began some of the earliest sensory storytimes, and was happy to share her time with me to give updates on inclusive library programming. Holly Jin shared programming ideas and tips, and her successes at shifting programs online. Becky Fesler is doing incredible inclusive advocacy work at her library, and shared example program plans for families.

Of course, this book wouldn't have been possible without contributions from members and supporters of the autism community, in particular its contributors: Steph Diorio, Tina Dolcetti, Karen Stoll Farrell, Charlie Remy, "Justin Spectrum," Kate Thompson, Adriana White, Paul Wyss, and Heidi Zuniga. I'm grateful to be accepted as an ally, and hope that this edition is a step in the right direction toward acceptance and inclusion. Individual biographies of these contributors are provided at the end of the book.

Thank you also to my incredible students at Old Dominion University, who submitted case studies and ideas for best practices in libraries. You will find

contributions from Sarah Brandow, Janet Coulson, Hope Hill Clark, Shannon Hoggatt, Karen Kinsey, Jessica Kompelien, Amber Langston, Jessica Lyszyk, and Reina Malakoff throughout the text.

I'm grateful to have had Jamie Santoro as an editor. She was always available to discuss progress and setbacks, and I was especially grateful for her guidance as I wrestled with my feelings of privilege and ally-ship. Jamie characterized my role in updating this book as being like the conductor of an autistic and allied orchestra—and I hope through this book that I've let all of these voices sing.

I can never thank Barbara Klipper enough for trusting me with making updates to her original work. I feel lucky to have been given such an excellent first edition to start from, and hope that my work on this second edition has made her proud.

Finally, I am so appreciative of my husband, Josh, who was incredibly encouraging as this book came together. I couldn't have done it without his support.

—*Amelia Anderson*

Introduction

I MET BARBARA KLIPPER FOR THE FIRST TIME AT THE “TARGETING AUTISM in Libraries” conference in 2018. As always, the event was inspiring and left me motivated to continue my work at the intersection of autism and libraries, bolstered by the self-advocates and allies I had met and learned from. On the final day of the conference, I noticed the name tag of the person behind me on the hotel shuttle—Barbara Klipper! This was a celebrity sighting for me, as I use and reference the first edition of her book often.

A few short months later, Barbara and I met again at the American Library Association (ALA) Annual Conference. She invited me to meet for coffee and a chat; little did I know that she had a bigger plan. After attending the “Targeting Autism in Libraries” conference and hearing from self-advocates, Barbara knew that her 2014 book needed a refresh. While the first edition accurately reflected the time in which it was published, there were new understandings and ideas that needed to be incorporated now. The book’s language, terminology, and approaches needed to be updated to reflect the understanding of autism self-advocates, and to help librarians become true allies of the autistic youth in their communities. The book needed to include autistic voices themselves, and it needed to reflect the new knowledge that has been learned about autism, as well as new initiatives that libraries have introduced since the original publication. To my great honor, Barbara asked if I would take the lead on this update.

When we know better, we do better, and such is the case with this book. In this edition, I use the word “autistic” very purposefully, instead of referring to a child or teen as someone “with autism.” This reflects the preferences of autistic self-advocates, who prefer identity-first, not person-first, language. This is an ongoing discussion, and I hope that no matter what your language preferences are, you will learn from the approaches provided in this book. A more nuanced discussion of language is provided in chapters 1 and 2.

When faced with updating this text, it was clear that the framing needed a major update. The program ideas provided in this book are incredibly rich and easy to replicate. My fear was that librarians would not read past the introductory chapters to access the program ideas, or else they would jump right to the

program ideas and miss the reasons for the approaches suggested and the best practices to follow, which were covered in the first chapters of the first edition and are repeated here with some modification.

In this edition, there are now new, replicable programs and updates provided for the examples of successful library programming in the previous edition. But the work of programming must be grounded in general knowledge and an introduction to autism, and that information needs to be current and correct. This has all been updated with what we know today.

Additionally, we all experienced a monumental shift in 2020 with the COVID-19 pandemic. Library services shifted online, and many programs still operate this way. To account for these changes, I have included virtual options throughout the book. Look for the “Make It Virtual” tag within the chapters for ideas about programs that could easily be done in a virtual environment.

This edition will present the currently accepted facts about autism, and what are seen as best practices, but as you read you should keep a few things in mind:

1. Ideally, libraries should offer multiple, primarily inclusive programs, train staff repeatedly and in different ways, and apply all of the suggested best practices. However, we all live with budget and time constraints, and we must work within the mandates of our library administrations. As you read and apply the ideas presented in this book, feel free to modify them, both to match the autistic children and teens you serve and to fit your library’s community and culture. Hopefully, if you have small successes, you will be able to build on them over time.
2. Our understanding of autism is constantly evolving, so what we know in 2021 may be seen as misguided in 2023. This continuous evolution is one reason for this second edition.
3. How autism is talked about may depend to some extent on who is doing the talking. Doctors and therapists, researchers, and parents may share common views about autism, or they may not. “Self-advocates,” the term often used for autistic people who speak on their own behalf, may have a totally different concept of what autism is. This book will try to give you both the professional and the self-advocate view.
4. I have been careful to operate from the assumption that there is nothing about autism that needs to be “fixed” or feared, which is primarily the view of self-advocates and their allies. But there are educational needs to be addressed and barriers removed if we wish to improve services for the autistic members of the community.

This edition presents the facts as objectively as possible, while acknowledging that some of these facts are fluid and somewhat subjective. The aim is always to provide information and approaches that can improve library visits and programs for the autistic youth and teens you serve. This edition amplifies the voices of autistic self-advocates, all of whom are librarians themselves. Their

voices were not included in the first edition, and that was a shortcoming of that book. It should be noted that these contributions were edited for length to be included in the printed text. These edits were made in careful collaboration with the authors, and no additional edits were made to change content, grammar, or otherwise alter the meaning of the original work.

I acknowledge my privilege as a non-autistic researcher, but I know that this privilege also allows me to provide a platform for those whose voices might otherwise not be heard. This edition amplifies the voices of autistic self-advocates, many of them librarians themselves. I am not autistic; I am a researcher, educator, and former public librarian. And as I hope I have demonstrated in this updated edition, I am also an ally.

There is still work to be done, but I hope that you find the second edition of this text even more approachable and valuable than the first. In the spirit of continual growth, I hope that you will reach out should you have questions or concerns about the approaches used in this text. Let's work together to move this conversation forward as we continually improve library services for the communities we serve.

—Amelia Anderson

How to Use This Book

AS BARBARA KLIPPER DESCRIBED IN THE FIRST EDITION, GIVEN THE prevalence of autism, there is a high price to pay when we avoid serving these community members and, by extension, their families. Every time an autistic child is not comfortable with or is unable to successfully use the library, that child's parents and siblings are not fully able to use this community resource either. These families are already isolated in many ways. We should not add to that isolation by effectively denying them access to one of our most important community institutions.

Our sincere hope is that this book will continue to provide librarians with a general comfort level, understanding of need, and easy-to-replicate ideas for successfully serving autistic children and teens in their communities.

Read the whole book, even if you think only one or two of the chapters apply to you. The material is arranged in a way that should be the most useful, but there is a lot of overlap. Many of the program ideas found in the chapter about schools, for example, can also work in a public library, and the introductory material in each chapter can also have broader applications.

The purpose of this book is to provide librarians who work with children and teens with enough information that they will no longer feel unprepared and fearful of working with autistic children and their families. Adults who work with young people in schools, community centers, and camps can also use the information and implement the programs found in this book.

You'll learn a little about autism, including how it manifests in behaviors, as well as some general guidelines for interacting with autistic people in a library setting. We'll introduce the things you need to consider as you design programming for this population, we will describe best practices, and we'll tell you how to select books and music to use in your programs. We'll also supply programming ideas for different age groups, along with general information that can guide you as you apply or adapt those program ideas to your own library. Throughout the book and in the appendixes you'll encounter many useful resources: books, articles, websites, organizations, vendors, and possible funding sources that can assist you.

Does this sound like a lot for you to learn? Don't worry—it's not. The things that you need for success in programming for autistic young people and their families are a basic understanding of the issues; a knowledge of where to find resources, information, and support; and a big heart. If you are reading this, the odds are that you already have a big heart. You will have this book to refer to for the rest. The hope is that this book will help you feel confident enough to offer programs that serve these children and teens in your community.

For Review Only

What Is Autism?

AUTISM IS CONSIDERED A SPECTRUM DISORDER BECAUSE OF THE wide-ranging types and severity of characteristics that people with the disorder display. A quote commonly attributed to Dr. Stephen Shore, a professor and autistic self-advocate, is: “If you’ve met one person with autism, you’ve met one person with autism.” The characteristics of autism manifest differently in every person with the disorder, and that is partly why the question, “What is autism?” is so hard to answer.

We can tell you what it is not. Autism is not a health crisis or a growing epidemic. It is something that is present in many of our children, family members, and peers—whether we realize it or not. Though often associated with children, autism is a lifelong disorder and can be diagnosed at any age. Some adults are diagnosed only when their children are evaluated for autism, and some adults we see as quirky or eccentric may actually be autistic and not realize it. However, even though diagnosis may not take place until later in life, autism falls under the umbrella of “developmental disorders” because it typically appears in childhood, and one does not suddenly become autistic later in life.

We won’t provide the full picture here, but we will give you enough information about autism to help you design or adapt appropriate programs for members of the autism community. Read on.

What Does Autism Look Like in Children and Teens?

In general, autistic children look like . . . children. Autistic children do not have distinguishing facial characteristics. They are not necessarily bigger or smaller than other children. They do not use a wheelchair, braces, or other mobility aids because of their autism. Sometimes autistic children do call attention to themselves, but usually this is by their behavior, not their physical characteristics.

At some point you may have seen a child displaying what might seem like inappropriate behavior in your library or another public place: crying or screaming for no apparent reason, talking to themselves, spinning in circles, walking

on their toes, or flapping their arms. The child may have stood too close to other people, not answered questions, refused to make eye contact, or walked away when someone addressed them. Their clothes may have been stained, chewed on, or torn, or their hair disheveled. And often their parent's repeated attempts to control them may have had no effect whatsoever. It's easy to assume that what you observed was an example of ineffective parenting, and while that may be true, it is equally possible, and perhaps more likely, that what you saw was an example of an autistic child who was not feeling comfortable. Many of those observable behaviors are actually the child's attempts to self-regulate. *Self-regulation* is the term for a person's ability to moderate their feelings when they are in situations that can provoke stress, anxiety, annoyance, or frustration.

You may see stimming behavior from children of any gender, not just boys. Statistics from the Centers for Disease Control (CDC) indicate that more boys than girls are diagnosed with autism spectrum disorder (ASD), but the truth is probably more complicated.¹ We can't be sure of the exact male-to-female ratio, and multiple theories exist as to why more males than females are diagnosed with ASD. While it is possible that males simply have a higher prevalence of autism, it might also be true that autism traits in females are underreported, that females are better at "masking" their differences, or that females have characteristics that don't fit within the traditional diagnostic criteria for autism. Some awareness of autism beyond the traditional male portrayal came in 2015, when *Sesame Street* introduced a female autistic puppet, Julia, on the popular program. (Note: While *Sesame Street* is still recommended as an excellent resource for autism education and materials, the Autistic Self Advocacy Network [ASAN] ended their partnership with *Sesame Street* in 2019 due to disagreements about their work with Autism Speaks.)²

Additionally, recent studies have revealed associations between autistic traits and gender variance, and a higher-than-average incidence of autistic people who also identify as GLBTQ.³ For all of these reasons, the singular pronouns "they/them/theirs" are used throughout this text.

What Is "Stimming"?

You might see a child or teen "stimming" in your library, and wonder what is going on. *Stimming* refers to self-stimulatory behavior that results in the repetition of movements or sounds. It may manifest as hand-flapping, rocking, pacing, or using a fidget object. Stimming can help a person self-regulate, and if it is not causing harm to themselves or others, it can be an important tool for autistics.

AUTISM IN GIRLS

Karen Stoll Farrell

I can see a meltdown building in my nine-year-old daughter's eyes. We are at a new restaurant, and the menu choices are different than they were on the website that we reviewed before coming. Now she is full of fear and rage, her normally rational brain short-circuited. When she was five, my husband took

her in for a diagnosis right after her older brother received his ASD diagnosis. We knew the bias against diagnosing girls with autism, but hoped that we had an edge as Autistic parents in explaining how her symptoms fit the spectrum. As it turned out, we were wrong.

The diagnostic criteria for autism, like many other medical diagnoses, were created over many years of working almost exclusively with boys. The current criteria are based very heavily on social skills and communication—which are, in turn, very heavily subjective and culturally created. As a society, we have recognized for decades now that we bring up girls and boys differently, especially in regard to how they communicate and socialize. The diagnostic criteria for autism do not recognize this difference.

Our now nine-year-old received a diagnosis of generalized anxiety. Upon receiving the explanation from the doctor's office, we discovered that she did meet the criteria for ASD, but that, in the doctor's "professional opinion", it was not the correct diagnosis. As it turns out, even when girls do meet the criteria, a doctor's bias can easily sweep all of that away.

We continue to feel the impact of this – it limits what insurance will cover, and it limits some social skills groups and camps that are specific about the need for an ASD diagnosis. However, these limitations are not the most difficult ones. The hardest ones stem from the ways in which our daughter presents differently from boys. She has always had difficult meltdowns, but almost exclusively at home, not out in public, and never at school; her inability to speak to strangers and her reticence in new environments are regularly written off as feminine "shyness"; her unwillingness to share toys, share in the creation of a game, and inability to understand social dynamics generally result in her quietly leaving a group of other children, rather than the outbursts of violence often seen in Autistic boys.

What all of this means is that she and we, as her parents, always have the burden of proof placed on us. From family members to teachers to strangers in restaurants and libraries, others look at our daughter and don't see that she is Autistic, opening the door for their judgment, and impacting further what assistance they are willing to offer our daughter.

Autism is lifelong. While we refer to autistic children and teens within this book, it is important to remember that those children and teens grow up—and are still autistic. Autism is not something that can be cured. While some autistic people develop strategies and approaches that help them better manage what might be uncomfortable manifestations of the disorder, autism does not go away. Though this book focuses on programming for children and teens, it will be helpful for you to remember that you are helping to provide supportive experiences for individuals who will grow up to be autistic adults. And just as with any other young library patrons, you are instilling a love of libraries at a young age, and building foundations for library use and patronage across the life span.

What Is Autism?

The Centers for Disease Control and Prevention (CDC) describes autism spectrum disorder (ASD) as “a developmental disability that can cause significant social, communication and behavioral challenges.”⁴

In contrast, the Autistic Self Advocacy Network (ASAN) calls autism “a developmental disability that affects how we experience the world around us. Autistic people are an important part of the world. Autism is a normal part of life, and makes us who we are.”⁵ It is important to acknowledge both of these understandings of what autism “is.”

The most comprehensive definition of autism can be found in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, or *DSM-5*, a collection of criteria that mental health and insurance professionals rely on to diagnose various disorders. The *DSM-5* is published by the American Psychiatric Association and is revised periodically.

According to the *DSM-5*, the diagnostic criteria for autism spectrum disorder include:

1. Persistent deficits in social communication and social interaction across multiple contexts
2. Restricted, repetitive patterns of behavior, interests, or activities⁶

These are the shortened criteria, but they should give you enough information to provide a solid baseline of understanding. If you want more detail, you may be interested in viewing the full diagnostic criteria.

In *DSM-5*, several conditions that once were diagnosed individually became subsumed under the broader diagnosis of ASD. Three of these are the ones we most commonly encounter: autistic disorder, Asperger syndrome, and pervasive developmental disorder—not otherwise specified, or PDD-NOS (which is pretty much what the name sounds like). You might think of ASD now as the umbrella term for what were formerly separate diagnoses.

In recent years, it was common to refer to someone who had autism as a “person with autism.” This is known as person-first language, and was used to reinforce the idea that the person is first and foremost a human being, and only in a secondary sense someone with a particular condition. By contrast, others use the terms “autistic person,” “autistic individual,” or (in the plural) “autistics” when referring to someone with the condition. This is known as identity-first language. While person-first language is still preferred by many other disability groups, autistic self-advocates and advocacy groups such as the Autistic Self Advocacy Network (ASAN) state their preference for identity-first language.

A Little History

Leo Kanner, a pediatric psychiatrist at the Johns Hopkins Hospital in Baltimore, was the first psychiatrist to clearly define autism. In “Autistic Disturbances of Affective Contact,” a landmark paper published in 1943, Kanner described eleven boys he had seen in his practice, and observed that they demonstrated “an extreme autistic aloneness that whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside.”⁷ Kanner noted that in addition to this extreme social isolation, the boys had a stronger attachment to objects than to people, displayed language and communication impairments, and had a strong aversion to change, obsessively needing everything in their world to remain constant. Kanner named this condition “early infantile autism,” which later became known as “autism.”

Autism was originally, and erroneously, thought to be a psychiatric condition related to schizophrenia. Kanner himself was an early proponent of this theory. He attributed his patients’ characteristics to bad parenting, which he principally defined by the presence of “refrigerator mothers” who were so cold, distant, and unloving that their children had no choice but to retreat from the world. This incorrect theory dominated the field for decades and was spread widely by Bruno Bettelheim in *The Empty Fortress: Infantile Autism and the Birth of the Self* (1967).

At about the same time that Kanner was publishing his work, Hans Asperger, a psychiatrist in Vienna, Austria, was observing boys who had an inability to empathize with others, difficulty in forming friendships, clumsy movements, and an extreme obsession with a special interest. While similar in some ways to the children described by Kanner, the boys that Asperger studied tended to have higher levels of cognitive, social-emotional, and linguistic functioning. In 1981, the British psychiatrist Lorna Wing identified children displaying this group of characteristics as having Asperger’s syndrome, a term that continued to be used until the publication of *DSM-5* in 2013.

One hero in the story of autism is Bernard Rimland, a psychologist with an autistic son. Rimland took exception to the bad-parenting theories and set out to debunk them. While Rimland is not widely known outside of the autism community, his contributions to the field were numerous and important. In *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (1964) he promoted an alternative, biological explanation for autism. In addition to writing this classic, Rimland founded both the Autism Society of America (ASA) and the Autism Research Institute (ARI), and he supported many experimental treatments that eventually became accepted as the standard of care for autistic people.

Today professionals accept that autism is a neurobiological condition with a genetic component, and researchers are working to identify the biological, genetic, and environmental influences that cause the condition. Although we have seen much progress in this regard, there is much that is still not known.

Because there is no accurate test for autism and our knowledge of the condition's etiology is sketchy, neither professionals nor families always agree on all aspects of how to help autistic children. The only thing we can say for sure is that nobody yet knows the whole story, and that incorrect, destructive theories (like that of the “refrigerator mother”) have demonstrated remarkable staying power. A more recent example of a long-lived and very harmful theory is the highly publicized idea that an additive in childhood vaccines causes autism. Although this conclusion was discredited with the admission that the original study was based on fraudulent data, it has refused to disappear from public view. The result is that some parents still believe it, refusing to vaccinate their children and creating significant public health consequences, such as the widespread measles outbreak in the United States in 2019.

What about Asperger Syndrome?

Arguably, an important transition from the *DSM-IV* (1994) to the *DSM-5* was the removal of Asperger syndrome as a stand-alone diagnosis.⁸ This transition has led to some clunky decisions, and many are still wrestling with the aftermath. To differentiate those who were formerly given an Asperger's diagnosis from those who were autistic, “functioning” labels were briefly adopted by some. Thankfully, the terms “high-functioning” and “low-functioning” did not stick around for long, as they carry with them extremely negative connotations.

People who formerly identified as having an Asperger syndrome diagnosis must now make a conceptual shift to the broader diagnosis of autism spectrum disorder. While straightforward for some, others have had a hard time mapping their identities to a new diagnosis. You may hear some older teen or young adult patrons describe themselves as having Asperger syndrome. In all cases, we should let people identify how they choose. While it would be inaccurate now to design programming for individuals with Asperger syndrome, if a teen identifies as such, try to mirror their language.

What is generally accepted now is that ASD, or simply “autism,” is the general term for anyone with an autism diagnosis, even those formerly diagnosed with Asperger syndrome. Assuming no major changes to future editions of the *DSM*, it is only a matter of time before the Asperger label disappears from the common vernacular.

WHO IS AN AUTISTIC PERSON?

“Justin Spectrum”

Who is an Autistic person? That person may have a formal diagnosis of autism spectrum disorder that is recognized by the *DSM-5*. However, autism is also an identity, which is why the term “Autistic” is being capitalized here. The

formal diagnosis is so often necessary for educational or workplace accommodations, but can be quite expensive.

I was diagnosed as a 34-year-old adult, and the bill for my psychological testing and related report was over \$3,000. I was fortunate enough to have premium health insurance, which reimbursed me for about two-thirds of this price tag under my out-of-network mental health coverage. Many therapists who diagnose and treat Autistics do not take insurance, and not everyone has out-of-network medical coverage or the resources to pay out of pocket and hope for a partial reimbursement. Due to these diagnosis and treatment barriers, many self-advocates argue that self-diagnosis or self-identification as Autistic should be considered valid.

While autism has historically been under-diagnosed, it has been well-documented that women and people of color are less likely to receive that diagnosis. Autism was initially identified in white men, and practitioners may be less likely to consider an autism diagnosis in a woman. The experience of Autistics of color has been narrated in an anthology called *All the Weight of Our Dreams: On Living Racialized Autism*. Lydia X. Z. Brown, in the introduction to this anthology, writes that “mainline autism and autistic organizations exist largely without us or with few autistics of color.”⁹ Brown also notes that nearly all major works on neurodiversity and Autistic politics have been produced by whites, with few contributions from Autistics of color.

Sensory Processing Disorders and Autism

The term *sensory processing* refers to the way our brains integrate the information we receive from our senses so that we can respond to it in physically or behaviorally appropriate ways. Most of this information comes to us through the familiar five senses (sight, hearing, touch, smell, and taste). We also get information from three additional senses: the proprioceptive (which allow us to know where we are in space and to have an idea of where our bodies begin and end), the vestibular (which tells us about our movement and balance), and the interoceptive (which provides information about what is going on internally in our bodies).

Sensory processing disorders (SPDs) are neurological conditions in which the body receives sensory information, but a neurological impairment prevents that information from being organized and interpreted by the brain in a way that results in inappropriate responses.

SPDs are extremely common; one recent study indicates that as many as one in twenty children may have some form of sensory processing disorder, while another study estimates that one in six children is affected.¹⁰ And while there are children with SPD who are not also autistic, almost every autistic child has

some degree of sensory processing disorder. In fact, in *DSM-5*, sensory processing issues are listed as one of the possible criteria for the diagnosis of ASD.

There are many ways that sensory processing disorders can affect the children and teens you see in your library:

- Sensitivity to tactile stimuli, indicated by resistance to certain textures, or discomfort with things like tags and seams in clothing. They may hate getting wet, touching clay or finger paint, or having dirty hands.
- Overreactions or underreactions to pain or noise.
- Sensory seeking, indicated by the child's need to touch everything, put things in their mouth, spin, or engage in other activities that give them lots of sensory input.
- Sensory avoidance, which is the opposite of sensory seeking. A child who feels bombarded by sensory input may seek out calm surroundings and become extremely distressed by crowds, noise, spicy foods, loud music, bright lights, or the touch of another person.
- Clumsiness, often manifested as stepping on toes or bumping into people or things. A child who has sensory discrimination problems may tear the paper when they write because they use too much force with their pen, pencil, or crayon.
- Poor motor planning, resulting from the inability to imagine a task, picture the steps needed, and then implement those steps in the correct sequence.
- Inability to follow directions, especially when the directions include more than a single step or action, or when they involve moving one's limbs across the midline of the body.
- Pain and frustration when the child cannot identify their physical feelings. For example, the child may know that their stomach hurts but can't determine whether they are hungry, have to go to the bathroom, or have another, more serious issue.

Because people with SPD can be either sensory avoiders or sensory seekers, you should be sure to offer sensory tools or activities that work for both groups. Calming activities and soft music will help sensory avoiders, but they will do nothing for those in need of sensory stimulation.

Autism Is a Disability

In this book, we mostly talk about autism in isolation, but it is important to remember that autism is a recognized disability, and autistic people are therefore included in more general disability-related laws and policies.

WHO IS A DISABLED PERSON UNDER U.S. LAW?

“Justin Spectrum”

Autism is a disability. It is defined as such under precedents in U.S. civil rights and education law going back to the 1970s, when laws were passed that were the predecessors of the Americans with Disabilities Act (ADA) and the Individuals with Disabilities in Education Act (IDEA) of 1990. An American is considered to be disabled under a “three-pronged” definition: if they have a physical or mental impairment that substantially limits one or more major life activities, have a record (i.e., medical documentation) of such an impairment, or are regarded as having such an impairment.¹¹ The ADAAA (ADA Amendments Act) of 2008 expanded the list of “major life activities” whose impairment constitutes disability, and added “major bodily functions” to this umbrella.¹²

IDEA and a series of court rulings over the past forty-five years have defined the concepts of a “free appropriate public education” (FAPE) and the “least restrictive environment” (LRE), and required disabled students to have an “individualized education plan” (IEP).¹³ Youth services library workers should familiarize themselves with these concepts and may find them applicable when planning programs to best include Autistic children and teens.

I was diagnosed with autism spectrum disorder, severity level 1 (what would have once been termed “Asperger’s syndrome”) as an adult. I have received no accommodations at any level of education, or in any workplace. Yet, under the three-pronged definition (discussed above), I am disabled. I have been diagnosed with a condition that impairs major life activities and bodily functions, and I have a record of this impairment: the report from my psychological testing.

The aforementioned ADAAA of 2008’s expanded list of “major life activities” includes communicating, speaking, and concentrating, all of which are impaired in some way by my autism. (Even though I am a speaking Autistic who deals with the public, I still have challenges with communication.) Furthermore, neurological and brain functions are considered major bodily functions. I am disabled under U.S. law as at least two of the prongs in the well-established definition apply to me, and autism has consistently been considered to be a disability under EEOC (Equal Employment Opportunity Commission) guidelines.

Along with these legal boundaries, one should consider the viewpoint of Autistic self-advocates. Amythest Schaber, in their *Ask an Autistic* series on their YouTube channel, explains why autism is a disability in episode 16. Some may not want to consider Autistics to be disabled because there may be a stigma attached to the term *disability*. However, autism is a

disability from a medical and legal viewpoint and by the consensus of self-advocates. While one can easily find T-shirts online declaring that autism is not a disability but a “difference” or a “superpower,” a deeper understanding of disability itself will encourage autism acceptance and even pride.

Neurodiversity

The neurodiversity movement is a phenomenon you should be aware of because it pertains to autism. In the 1990s Judy Singer, a sociologist and autistic self-advocate, coined the term *neurodiversity* to represent variations in the human brain. As this term continues to gain popularity, you might hear it used interchangeably with *autism*, which is not entirely correct. While autism is one form of neurodiversity, other neurological conditions or disorders such as attention deficit hyperactivity disorder (ADHD), dyslexia, and Tourette’s syndrome also fall under the neurodiversity umbrella. The neurodiversity movement operates under the assumption that neurological variations are not flaws, but instead should be seen as diversity. The movement also draws from elements of the social model of disability, which essentially claims that a person is disabled when society presents barriers to make it so. This is a complex set of theories and thoughts, and we don’t want to overwhelm you with too much detail here. If you want to further your knowledge, there are many resources you can easily find that can provide more information about both neurodiversity and the social model of disability.

LIBRARY SERVICES THROUGH A DISABILITY STUDIES LENS

“Justin Spectrum”

The field of disability studies positions disability as being first and foremost socially constructed. Impairment (e.g., a wheelchair user’s mobility impairment) is real; disability is the result of a world that is not designed for people with those impairments. To look at autism and Autistic people through a “disability studies lens” offers a clear path to acceptance. Why can’t Autistic people fully participate in your library? Should the structure of the library itself, the facilities and policies, be examined more for their role in constructing barriers?

Surely, you are “aware” of autism. That awareness may lead you to recommend a book like *Rules* (2006) by Cynthia Lord, which was positively reviewed at the time and earned a Newbery Honor. Riki Entz, writing for the *Disability in Kidlit* blog in 2015, offered a different perspective. *Rules* is

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