

PROGRAMMING
FOR CHILDREN AND TEENS WITH
AUTISM SPECTRUM
DISORDER

ALA Editions purchases fund advocacy, awareness, and accreditation programs for library professionals worldwide.

PROGRAMMING
FOR CHILDREN AND TEENS WITH
AUTISM SPECTRUM
DISORDER

BARBARA KLIPPER



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BARBARA KLIPPER has been involved with people with autism since 1986, when the first of her two sons to have this disorder was diagnosed. She and her husband were founding parents of Giant Steps, a school for children with autism in Fairfield, Connecticut. In 2002 she was asked to develop the Special Needs Center collection for The Ferguson Library in Stamford, Connecticut, and since then she has been able to combine her interests in librarianship and service to children with disabilities. Barbara developed The Ferguson Library's grant-funded sensory storytime program, and she has presented at conferences and trained librarians from around the country in autism awareness and sensory storytime programming. An active member of the American Library Association, Barbara has chaired the Library Services for Special Population Children and Their Caregivers Committee and served on the Schneider Family Book Award jury and the ALA Accessibility Assembly.

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*For my wonderful family: my husband, David Daniel,
and my two adult sons, Michael and Matt. And for
everyone who lives with and loves a person with ASD.*

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foreword

FIVE YEARS AGO, DAN WEISS AND I SEARCHED HIGH AND low in library literature for information to start our library customer service project for individuals on the spectrum here in New Jersey. We were shocked to find virtually nothing dealing with patrons with autism spectrum disorder. Many hard-working librarians were creating inspirational projects for individuals with other disabilities, and certainly many people involved with ASCLA were champions of making our libraries more inclusive and welcoming. Yet the area of cognitive disabilities seemed to be absent. We worked with local health agencies and our regional library cooperative to start our *Libraries and Autism: We're Connected* program and website, and we immediately saw the need to disseminate our new knowledge to other library staff. Since then, we have brought our training to many sites throughout the United States, always finding people eager to better serve these individuals.

I am so enthusiastic about Barbara's book. She has assembled an excellent compilation of the many exciting and replicable programs happening throughout the United States and Canada. Some of these ideas are more ambitious than others, but they all have the same goals—bringing families and individuals with autism spectrum disorder (ASD) into our library buildings and better educating staff and patrons alike about the growing numbers of people diagnosed with ASD. Important things are happening everywhere, and we all need to get on board.

Be very clear—you do have many families with ASD in your own community; and with a very little effort, they may well become your most loyal and ardent

supporters as we have found to be the case here. This book holds everything you need to understand about why library programming and services need to be available in every library. Better yet, you will learn how to get started in a nonthreatening and instructive way.

Be brave and sample Barbara's many ideas. I guarantee you will become inspired to become an advocate to make your own library inclusive and proactive for all customers and especially those with autism spectrum disorder.

—Meg Kolaya

Kolaya is director of the Scotch Plains Public Library in Scotch Plains, New Jersey. With Dan Weiss, director of the Fanwood Memorial Library in Fanwood, New Jersey, Kolaya developed the Libraries and Autism: We're Connected program and website, www.librariesandautism.org.

acknowledgments

T

HIS BOOK WOULD NOT HAVE BEEN POSSIBLE WITHOUT the expertise of the many librarians and ASD professionals who so generously shared their time, their knowledge, and their ideas with me. They include:

Dr. Mark Greenstein, who many years ago introduced me to the idea of comparing autism to plaid, and who generously shared his thoughts with me for this book.

Speech pathologist Beverly Montgomery, who copresented with me at a New England Library Association Conference in 2009. Ms. Montgomery gave the clearest explanation I'd ever heard about the relationship between the features of ASD, text comprehension, and reading preferences. In an interview in 2012, she also generously shared programs that she'd done with students through the years, so that I could offer them to librarians in this volume.

Music therapist Dori Berger, who worked with my son Matt for many years, and who shared with me her very helpful thoughts about how to select music for children with ASD.

Art therapists and educators Michelle López and Jennifer Candiano, whose work with the Queens Library and with children and teens with ASD at the Queens Museum of Art is a model of successful programming and collaboration.

Thank you to librarians everywhere who provide programming for children, teens, and families with ASD, especially the many who so graciously shared their stories and their programs with me for this book.

Thanks also to friends and professional colleagues who read drafts of this book and offered suggestions and comments:

Speech language pathologist Vonnie Neufield, a good friend, who lent her ear and her expertise, and who shared part of this book with the librarians at the Danbury, Connecticut, school where she works.

Carrie Banks, director of the Child's Place for Children with Special Needs at Brooklyn Public Library, a mentor and friend, who gave me ongoing support and encouragement.

Heather Dieffenbach, whose presentation, "Programming for the Spectrum: Developing Inclusive Children's Programs for Children on the Autism Spectrum," developed when she worked at the Lexington, Kentucky, library, influenced me as I developed The Ferguson Library's sensory storytime program.

Gail Karlitz, a friend who read numerous drafts with a trained eye, and whose comments and expertise made this a much better book than it would have been without her input.

Thanks also to Caroline Ward, youth services coordinator at The Ferguson Library, who introduced me to involvement in ALA, and who offered me, a part-timer, the rare opportunity to introduce new ideas and develop programs like Sensory Storytime.

Special thanks go to my husband, who not only read and commented on a number of different versions of this book, but who cheered me on throughout the process of bringing this project to life.

And this wouldn't be complete without an expression of gratitude for my wonderful editor at ALA Editions, Stephanie Zvirin, who approached me at a conference and asked if I had ever considered writing a book on this topic. She not only planted the seed, she watered it and harvested the fruit.

introduction

IN APRIL 2013, THE CENTERS FOR DISEASE CONTROL RELEASED ITS latest statistics on the incidence of autism. Data collected from 2011–12 indicated that about one in every fifty children in the United States had an autism spectrum disorder, or ASD. Just a decade earlier, the incidence was one in 150.¹ What was relatively rare a generation ago has become epidemic.

There has been a lot of conjecture in scientific literature as well as popular media about the reasons for this increase, and it is probably due to a complex combination of better diagnostic tools, overdiagnosis, and an actual increase in affected children. Whatever the cause, this statistic is frightening, and it has implications for us as individuals and for our public institutions, including our schools and public libraries.

It is difficult to comprehend the impact of a statistic—to translate a number into a picture of real people. In the case of kids and teens with ASD, however, it is important that librarians who serve youth attempt to make that conceptual leap. The real people behind the numbers are girls and boys in our communities, girls and boys we may already be encountering in our libraries or, more sadly, whom we may not be seeing because we are not providing what they and their families need to feel safe and welcome. This is not because librarians and other library staff do not care about these children and their families. Rather, this failure to provide appropriate programming has to do with ignorance of these disorders and the fear that grows out of ignorance. These fears typically include the anticipation of a child having a meltdown or tantrum and the anxiety that we won't know what to say or do with children when they act differently from others their age.

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 a child with ASD is not comfortable with and able to successfully use the library, his 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.

The purpose of this book is to provide librarians who work with children and teens enough information so that they will no longer feel unprepared and fearful of working with children with ASD 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 people with autism in a library setting. I'll introduce the things you need to consider as you design programming for this population, describe best practices, and tell you how to select books and music to use in your programs. I'll also supply programming ideas for different age groups, including general information that can guide you as you apply or adapt those ideas to your own library. Whenever possible, I'll give you suggestions for lower-priced alternatives when costly materials are used. Throughout the book and in appendix A 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. Keep in mind that you do not need to be an autism professional to work with these kids. I'm not one myself. I am a youth services public librarian and the mother of two adult sons who have ASD. Those are my only credentials. I am not a scientist, a doctor, a special education teacher, or a therapist. I developed an expertise in programming for these children because I was the right person in the right place at the right time. Let me explain.

About a decade ago, a community resident approached the president of The Ferguson Library in Stamford, Connecticut, suggesting the library start a collection of materials for parents whose children had disabilities. Because I was part of the youth services staff at The Ferguson and because I was the mother of children with disabilities, I was enlisted to work on the grant proposal and to develop what became the library's Special Needs Center. As a result of that experience, I became involved with the Americans with Disabilities Act (ADA) Committee of the Connecticut Library Association and did a number of presentations on disabilities and autism in my home state and elsewhere in New England. My work on the Special Needs Center also led me to Carrie Banks from

A Note About the Book

I suggest you read the whole book, even if you think only one or two of the chapters apply to you. I tried to arrange the material in the way that would be most useful, but the categories are somewhat arbitrary and 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 application.

Brooklyn’s Child’s Place for Children with Special Needs, who encouraged me to become involved in American Library Association committees and groups that support service for people with disabilities. I served on, and later chaired, the Library Service to Special Population Children and Their Caregivers Committee of the Association for Library Services to Children (ALSC). I also designed the library’s Sensory Storytime program and wrote the proposal for the grant that funded it. I’ll describe that program in detail later in this book. That experience led me to share these programs with other librarians in talks, workshops, a webinar, and now with this book.

Throughout this journey, I used my research and outreach skills to connect with autism professionals and to learn what I needed to know. Now that I am something of an expert in this field, I want to share with you what I’ve learned. I’ll save you from the need to do your own research, and I’ll provide you with the information you need to do this work and to do it well. The only things that you really need for success in programming for young people with ASD and their families are a little knowledge and a big heart. If you are reading this, odds are that you already have the big heart. I hope that this book will help you feel confident enough to offer programs that serve these children and teens in your community.

NOTE

1. Centers for Disease Control and Prevention, “CDC Reports 1 in 50 Children Diagnosed with Autism,” www.nvic.org/NVIC-Vaccine-News/April-2013/CDC-Reports-1-in-50-American-Children-Diagnosed-wi.aspx.

WHAT IS AUTISM?

I T IS FITTING THAT THE WIDELY ACCEPTED SYMBOL FOR AUTISM IS A jigsaw puzzle piece and that the Autism Awareness ribbon displays a collection of these colored jigsaw puzzle pieces. Autism is puzzling to family members and professionals, and the world is puzzling to people with autism. To help you work more effectively in a library setting with children and teens with autism, I'll provide you with a few pieces of the puzzle. I can't give you the entire picture because no one knows what that is, but I can give you enough information to help you design or adapt appropriate programs for this population.

What Does Autism Look Like?

In general, children with autism tend to look like . . . children. Children with autism generally 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. Children with autism sometimes call attention to themselves, but usually this is by their behavior.

At some point you may have seen a child acting inappropriately in your library or another public place, crying or screaming for no apparent reason, talking to himself, spinning in circles, walking on his toes, or flapping his arms. He may have stood too close to other people, not answered questions, refused to make eye contact, or walked away when someone addressed him. His clothes may have been stained, chewed on, or torn, his hair disheveled. And often his parent's repeated attempts to control him may have had absolutely no impact.

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 a child with autism who was not functioning at his best.

A Basic Definition

Autism spectrum disorder is a neurobiological condition that begins in early childhood. It is characterized by impairment in social interaction and communication and by the presence of restricted or repetitive behaviors.

A Little History

Autism was originally, and erroneously, thought to be a psychiatric condition related to schizophrenia, and Leo Kanner, a pediatric psychiatrist at Johns Hopkins Hospital in Baltimore, Maryland, was an early proponent of this theory. In a paper published in 1943, he described eleven boys he saw in his practice, saying that they demonstrated “an extreme autistic aloneness that whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside.”¹ Kanner also 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 stay constant.

Kanner attributed his patients' characteristics to bad parenting, 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 and destructive 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* (Free Press, 1967).

At about the same time as 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, British psychiatrist Lorna Wing identified children displaying this group of characteristics as having *Asperger's syndrome*, a term that continues to be used.

What to Call It

It is common usage today to refer to someone who has any type of a disability as a “person with ____.” So, in this book I use the phrase *child with autism*, not *autistic child*. This is known as people-first language, and it reinforces the idea that the person is first and foremost a child and, only in a secondary sense, someone with a particular condition.

The official term is *autism spectrum disorder* (ASD), but in this book I use the term *autism* to refer to the entire spectrum and *Asperger's* to refer to those on the higher-functioning end of the spectrum. While that is not completely accurate, it is precise enough for our purposes. In the library, you probably won't know an individual's label anyway. I also refer to people with autism with the pronouns *he* and *him*. This is not to ignore gender sensitivity, but to acknowledge the fact that there have been five times as many males as females diagnosed with autism.

One hero in the story of autism is Bernard Rimland, a psychologist with a son who has autism. 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 are numerous. In *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (Prentice-Hall, 1964), he promoted an alternate, 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 supported many experimental treatments that eventually became accepted as the standard of care.

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

Because there is no test for autism and our knowledge of the etiology is sketchy, neither professionals nor families always agree on all aspects of how to help children with autism. Some believe autism can be cured by special diets or therapies; others don't. Some treatments like speech and occupational therapy are widely accepted; others, like the removal of heavy metals from the body, are controversial. 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) can have remarkable staying power. A more recent example of a long-lived (and ultimately 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 the potential for significant public health consequences.

A More Technical Definition

The most comprehensive definition of autism can be found in the *Diagnostic and Statistical Manual of Mental Illness* (known as the DSM), a collection of criteria that mental health and insurance professionals rely on to diagnose various disorders. The DSM is published by the American Psychiatric Association and is revised periodically.

DSM-IV TR, the edition published in 2000, includes a category called autism spectrum disorders, made up of five pervasive developmental disorders. Three of these are the ones we most commonly encounter: autistic disorder (which corresponds roughly to Kanner's definition of autism), Asperger's syndrome, and pervasive developmental disorder—not otherwise specified, or PDD-NOS (which is pretty much what the name sounds like).

According to that edition of the DSM, for a diagnosis of autism, symptoms had to be present in three areas—social reciprocity, communicative intent, and restricted and repetitive behaviors.

In DSM-5, a revision published in 2013, the first and second symptom groups became one category called social communication/interaction.² The subsets, including Asperger's syndrome, were eliminated, leaving one diagnosis, autism spectrum disorder. These changes in the criteria were intended to simplify the diagnostic process; however, they have precipitated much controversy in the autism world. Many parents and professionals are concerned that higher-functioning individuals who would formerly have been diagnosed with Asperger's syndrome will no longer meet the criteria of this new classification and will be deemed ineligible for needed services. This change in the diagnostic criteria may also serve to falsely lower the autism incidence rate as people now labeled ASD receive other diagnoses.

The Components of Autism—Think about Plaid

Dr. Mark A. Greenstein, a pediatrician who is trained and certified in both genetics and developmental pediatrics, has worked with many children with autism during his long career. He compares the autism spectrum to the familiar fabric pattern known as plaid. To be considered a plaid, a pattern must have three elements: bars or stripes, right angles, and color changes where the bars or stripes intersect. Although there is much variation among plaids, a pattern that is missing one or more of these elements is not a true plaid. In a similar way, a disorder that does not affect all three areas (social interaction, communication, and restricted and repetitive behaviors) cannot be considered to be an example of autism, even though it may be like autism in some ways.

As with plaids, which can be anything from muted to garish, autism can be subtle or glaring, and each of the three elements that must be present for a diagnosis of autism can manifest in many ways. Impairment in social interaction, for example, can include people who never interact with others at all as well as people who try to interact with others all of the time but often don't know how to do it. Impairment in social communication can refer to people who are almost totally nonverbal as well as those who speak nonstop or who use language in a very pedantic way. Restricted and repetitive behaviors may include those who follow rituals when dressing or eating as well as people who develop extraordinary expertise in an obscure area of knowledge.

Sensory Processing Disorders (SPD) and Autism

Sensory processing refers to the way our bodies integrate the information we receive from the environment so we can respond to it in physically or behaviorally appropriate ways. Some of this information comes to us through the familiar five senses (sight, hearing, touch, smell, and taste). We also get infor-

mation 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 movement and balance), and the interoceptive (which provides information about what is going on internally in our bodies).

When someone has a sensory processing disorder (SPD), the body receives sensory information, but a neurological impairment prevents that information from being organized and interpreted in a way that results in appropriate responses. This is different from sensory impairments like deafness.

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.³ And, while there are children with SPD who are not on the autism spectrum, almost every child with autism 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 you see in your library:

- Oversensitivity to tactile stimuli, indicated by resistance to certain textures or discomfort with things like tags and seams in clothing. The child may hate getting wet, touching clay or finger paint, or having dirty hands.
- Over- or underreactions to pain or noise.
- Sensory seeking, indicated by the child's need to touch everything, put things in his mouth, spin, or engage in other activities that give him lots of sensory input.
- Sensory avoidance, the opposite of sensory seeking. A child who feels bombarded by sensory input may seek out calm, becoming extremely distressed by crowds, noise, spicy foods, loud music, bright lights, or the touch of another person.
- Extreme clumsiness, frequently stepping on toes or bumping into people or things. A child who has sensory discrimination problems may tear the paper when he writes because he uses too much force with his 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 his physical feelings. For example, he may know that his stomach hurts but can't determine if he is hungry, has to go to the bathroom, or has another, more serious issue.

Feeling Overwhelmed? Relax

Remember: You don't have to be an expert to work with these children, and each chapter will give you more information to guide you. Parents and professionals are also available to provide you with information and support. For example, many children who have been identified as having autism or sensory processing issues work with sensory integration occupational therapists in their schools or privately. These therapists can be a valuable resource for you if you want to know more about SPD or how to incorporate activities that promote sensory integration into your programs. There are also books and websites listed in appendix A that can give you more insight into both autism and SPD.

NOTES

1. Leo Kanner, "Autistic Disturbances of Affective Contact," *Nervous Child* 2 (1943): 217–250.
2. DSM numbering system changed from Roman to Arabic numerals beginning with the 2013 revision, DSM-5.
3. Roianne Ahn, Lucy Jane Miller, et al., "Prevalence of Parents' Perceptions of Sensory Processing Disorders Among Kindergarten Children," *American Journal of Occupational Therapy* 58, no. 3 (2004): 287–293. Also A. Ben-Sasson, A. S. Carter, and M. J. Briggs-Gowen, "Sensory Over-Responsivity in Elementary School: Prevalence and Social-Emotional Correlates," *Journal of Abnormal Child Psychology* 37 (2009): 705–776. Both at www.spdfoundation.net.

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