



**LIBRARY PROGRAMMING**

# **FOR ADULTS WITH DEVELOPMENTAL DISABILITIES**

**Barbara Klipper and Carrie Scott Banks**



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# Introduction

This book's contents grew out of our combined experiences and work on this topic over many years. We supplemented that with extensive reading as well as interviews with librarians and other professionals who we feel are ahead of the curve in terms of what they offer for the adults with developmental disabilities (DD) who live in their communities. Our goal is to provide a context for serving adults with DD, offer a wide variety of program ideas you can implement, and support you in creating a culture of inclusion in your library. Our hope is that all adults who walk through the door of a library, regardless of their cognition, communication style, behavior, or appearance, will be treated respectfully and will find themselves welcomed and valued by a knowledgeable staff.

Some of what we discuss affects everyone in the library and community; however, our focus is on adults with DD and their needs. So, what are developmental disabilities? There are as many answers to that question as there are people to answer it. Congress uses a legalistic view, the Centers for Disease Control and Prevention (CDC) a medical one, and self-advocates a third, strengths-based definition. In the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), which is the main source of government funding for DD services, Congress defines DD as

a severe, chronic disability . . . attributable to a mental [and/]or physical impairment . . . [that] manifest[s] before . . . age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more . . . areas of major life activity . . . ; and reflects the individual's need for . . . services, individualized supports, or other forms of assistance that are of lifelong or extended duration.<sup>1</sup>

The CDC emphasizes the conditions that fall under the DD umbrella, although no two groups who list specific disabilities include all of the same ones.

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In sharp contrast to these definitions is that of the Autistic Self Advocacy Network (ASAN): "Autistic people have a unique set of characteristics, which can manifest as difference, disability, or gifts/skills, from person to person and within the same person."<sup>2</sup> Unlike the medical and government-generated definitions, the ASAN one focuses on attributes not deficits and is embraced by many self-advocates.

### DEFINING DEVELOPMENTAL DISABILITIES

Common elements in DD definitions:

- The disability starts in childhood, before age twenty-two.
- It is a lifelong disability.
- Intellectual disabilities and autism are included.

Developmental disabilities impact:

- communication
- behavior
- cognition
- day-to-day living

Because they are always included in definitions of DD, we focus primarily, but not exclusively, on autism, officially called autism spectrum disorder (ASD), and intellectual disabilities (ID).

We made some other choices as we developed the book that you should understand before you read further:

- The term *self-advocate* appears throughout. It comes from the self-advocacy civil rights movement begun in the 1960s, which is based on "the idea that people with disabilities have the right to speak up for themselves. People with disabilities also have the right to choose the services they want."<sup>3</sup> We consulted and quote self-advocates when possible because they are the true experts on their experience and needs.
- We frequently mention those adults with DD who come to the library in groups escorted by agency personnel. We do this because these groups use many public libraries, and a number of the programs we present were designed for them or include them as participants. However, people in congregate housing or those who attend day programs are not the only

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adults with DD. In fact, those in residential programs represent only about 13 percent of people with DD.<sup>4</sup> Many others use our libraries independently or are accompanied by a parent or other caregiver, and still others are not library users. There are library staff with DD, including librarians. Libraries need to serve all of these individuals as well as the groups.

- The book contains an extensive discussion of current terminology. With this in mind, we use *people with developmental disabilities*, which is an example of person-first language, but we also use *autistic people*, which is an example of identity-first language. These choices reflect the preference of self-advocates.
- We use the term *developmental disabilities* (DD) throughout, although some quotes use *intellectual and developmental disabilities* (IDD). Both are in current use, but ID is technically a subset of DD.
- The word *focused* is used to denote programs designed specifically for people with disabilities. *Inclusive* programs are those for people with disabilities and the nondisabled, participating together. Not all programs will work well for every patron, so we introduce both types to help you serve the widest variety of adults with DD.
- As used in this book, a social story is a linear narrative, usually with visuals, that describes a situation or experience in order to make it more comprehensible and predictable for autistic people. This is a widespread, though imprecise, use of the term as developed and defined by Carol Gray.
- As we wrote this book, libraries experienced a seismic change in how they operate because of the COVID-19 pandemic. Most of the in-person programs we were writing about were suspended. Some went virtual. We don't know how many of these will be impacted when their libraries return to full service; however, they still represent good, replicable ideas, so we share them. We hope the new postpandemic programming model has inclusion at its core and retains the best of in-person and virtual programming.
- Because it is new to so many of us, we include guidance on virtual programming, both in a dedicated chapter and throughout the volume.
- We intend this book to be both inspirational and aspirational. We realize that many libraries will not be able to implement anywhere near all of the things that we suggest in the near term. However, we want to present what we believe is the ideal, allowing readers to decide on the best starting point for their own institutions and communities while understanding what they can aspire to and move toward over time.

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Underlying the premise of the book is the understanding that people with DD have the right, as codified by several laws, to full access to our libraries. The DD Act and the better-known Americans with Disabilities Act (ADA), which prohibits disability-based discrimination, are the primary civil rights laws covering people with DD. The Individuals with Disabilities Education Act (IDEA), which covers students with disabilities between the ages of eighteen and twenty-two, and the Higher Education Opportunity Act (HEOA) are also important. IDEA funds services such as employment and daily living skills training and provides opportunities for community involvement for transitioning high school students. Many transition groups use our libraries, and in the pages that follow, we introduce some programs done with and for these groups. HEOA provides access to student loans and prohibits discrimination by institutions of higher education, enabling many more students with DD to attend colleges and universities. Because of this law, academic libraries work with increasing numbers of students with DD. There are also state and local laws that may confer additional rights. It is a good idea to know about those as well.

What these laws have in common is the understanding that people with DD are full members of society and should be treated as such. As the DD Act states:

[D]isability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.<sup>5</sup>

Our professional standards also mandate full inclusion. The American Library Association (ALA)

recognizes that people with disabilities are a large and vibrant part of society. Libraries should be fully inclusive of all members of their community and strive to break down barriers to access. The library can play a transformational role in helping facilitate more complete participation in society by providing fully accessible resources and services.<sup>6</sup>

Our aim is to help you break down barriers and achieve full inclusion in your libraries, in part through programming. To do that, we start with general concepts and issues that are important to understand, then move to specific programs you can replicate and resources you can use. Part I discusses institutional ableism and



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the ideas and biases that impact the lives of people with developmental disabilities. It also explains how to create a library-wide culture of inclusion. Part II describes how libraries can prepare for programming and presents a variety of elements to put in place to ensure programming success. Part III introduces a large assortment of programs, organized by topic. Because some programs are multifaceted and others don't easily fit into these somewhat arbitrary groupings, we suggest you consider all of the chapters in this section as you look for program ideas for your library. You might find some that would be perfect for your community in a chapter that didn't initially appeal to you. In the final section, we talk about what to do after reading the book and provide a number of resources to help you stay up-to-date on this ever-changing topic. Finally, we leave you with a list of best practices to follow as you begin to program.

Now that you know some basics and what we will cover, you're ready to get into the meat of the book. We hope you don't read it through once and shelve it. Rather, we hope you refer to this volume often, dog-ear your favorite pages, write in the margins, share favorite ideas and programs with colleagues, and even spill your coffee on it, if unavoidable. We'd like to see you make this book your own, and then apply what you find here in your library. Learning this material is not an academic exercise. There will be no grades. Rather, the work you do to create a culture of inclusion in your library and programming that truly serves adults with DD will affect the lives of real people in your community. It also has the potential to have a meaningful and positive impact on your institution, and on you.

## NOTES

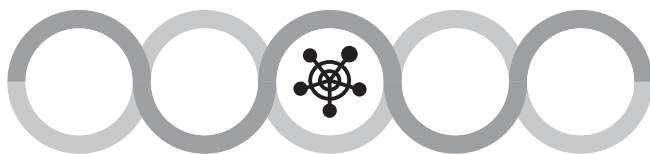
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PART I

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**Developmental  
Disabilities, Inclusion,  
and Support**

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## CHAPTER 1

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# Perception and Self-Perception

The ways in which individuals and society perceive people with developmental disabilities have a profound effect on our ability to program inclusively, so we start with an examination of these issues. The first thing to know is that despite the existence of laws and policies that call for inclusion, people with DD experience rampant discrimination called ableism.

### **BIAS AND INSTITUTIONAL ABLEISM**

Ableism is the parallel to racism and sexism. Institutional ableism is the set of laws, policies, regulations, practices, and cultural norms that prevent the full participation of people with disabilities in society. Institutional ableism has dominated the lives of people with DD for generations, creating and maintaining discrimination in every area of life, including education, employment, health care, benefits, housing, and the criminal justice system. One example of this is the fact that Medicaid pays higher reimbursement rates for services provided in nursing homes than it does for services offered at home. This pushes people who need services into congregate care facilities. In libraries institutional ableism manifests in such practices as having fixed loan periods that do not account for varied reading and comprehension speeds, requiring a noninstitutional address to get a library card, building high desks at points of service, and writing job descriptions that require librarians be able to lift fifty pounds of books.

## Challenging the Dominant Narrative

The dominant narrative about people with disabilities is simultaneously created by and supportive of institutional ableism. We are told, tell ourselves, and share with others stories comprised predominantly of negative myths and stereotypes. To explain this, let's go back to the Medicaid example. The dominant narrative asserts that many adults with DD are not capable of making decisions for themselves and living independently. This stereotype justifies the belief that adults with some conditions like ID get better care in institutions than they do at home in the community. Medicaid policy then pushes these people into congregate care. We accept the fact that they are institutionalized because we accept the narrative. It is a circular trap, and it hurts everyone.

The truth about individuals with DD is quite different from the dominant narrative. It is certainly more nuanced. Did you know that there are people with DD who

- live independently and have numerous responsibilities?
- are musicians, artists, doctors, teachers, actors, writers, carpenters, or athletes?
- go to community colleges or universities or have PhDs?
- have hobbies they enjoy and a myriad of interests and tastes?
- like to read many genres in a variety of formats?
- work in service, manufacturing, information, finance, child care, education, retail, farming, and every other sector?
- had autism as children and continue to have autism as adults?
- are strong advocates for themselves and others and accomplished public speakers?
- communicate in many ways: verbally, with augmentative and alternative communication (AAC), i.e., sign language, pictograms, or electronic devices?
- are single, married, birth parents, adoptive parents, transgender, gender queer, gay, heteronormative, or bisexual?
- speak every language and sometimes more than one?
- come from every culture in the world?

We mentioned that many common stereotypes are negative; some are also infantilizing. As autistic mental health advocate Emily Burke posted on Twitter:

I may have interests which you judge to be "childlike," get excited over small things which you also judge to be "childlike" and my autistic joy may come across to you as me acting "childlike," but none of these judgements you have mean you can treat me like a child.<sup>1</sup>

Not all stereotypes are negative, however, at least not on the surface. For example, people with Down syndrome are commonly thought to be sweet and friendly; people with the type of autism we used to call Aspergers syndrome are expected to be smart and excel in technical fields. Despite their seeming positivity, these stereotypes are also harmful because they are othering and one-dimensional.

The bottom line is that there isn't a typical person with a developmental disability. There are adults with DD who have high support needs and others who do not. Some adults with DD have notable achievements in one area and need supports in another. Some don't need supports at all. They are all unique individuals with strengths and talents in addition to things they don't do well, just like everyone else. Our patrons will be better served if we ignore the stereotypes, dismantle institutional ableism, and focus on the work of including everyone.

### **How Libraries Can Counter the Narrative**

Institutional ableism is perpetuated through the placement of people with DD in special, segregated schools or classes as well as in institutions. Isolating them from the community in these ways allows misperceptions to continue and hinders us all from moving beyond the dominant narrative. One way to counter this is to get to know individuals with DD. Librarians who do this report very positive experiences. For example, Nataya Culler from Brooklyn Public Library acknowledges that she was anxious and had misconceptions before she started programming for adults with DD, but with time and familiarity her feelings changed. She concludes, "There needs to be more . . . exposure. Because I feel like a lot of people have a nervousness and stigma . . . I'm not going to lie, I had the same nervousness, but after a couple of months it went away."<sup>2</sup> Renee Grassi of the Dakota (MN) County Library goes even further, saying of that library's staff, "We are becoming champions for accessibility as we become more aware."<sup>3</sup>

### **MODELS OF DISABILITY**

It is also useful to know a bit about the four basic models through which society views disability. Traditionally, the most widely accepted of these have been the predominantly negative medical and charity models. The medical model views disability as a disease to be cured. It focuses on medication and assistive devices to "fix" disability. The charity model, based on the ableist assumption that people with disabilities are inferior to the nondisabled, leads to pity, not empathy, and the belief that people with DD need to be taken care of, whether they want that or not.

Since the 1970s, disability activists, self-advocates, and allies have argued for and adopted new stigma-free models of disability, including the social model, which sees the problem as lying not with individuals with disabilities but with the barriers imposed by a society that fails to meet their needs. Lisa Rutledge, a woman with cerebral palsy, explains:

[The social] model makes a distinction between disability and impairment. . . . The model suggests that if biases are overcome and access barriers are removed, a person with impairments will have less of an experience of being disabled. Having impairments is a condition, while having a disability is an experience—one that can change, even if the person's condition does not change.<sup>4</sup>

Another model considers discrimination against people with disabilities a human rights issue given that disability is a natural aspect of the human condition. The latter two models align with the concept of institutional racism; in both, the emphasis is on a society that prevents access. So, with this in mind, as library workers, will we expect people with disabilities to change things in themselves that they cannot change or act to take down the barriers that exist in our institutions? This book offers many suggestions on how to go about removing barriers if we are willing to take action.

## UNDERSTANDING BEHAVIOR

Some library staff avoid interacting with or programming for people with developmental disabilities out of concern about behaviors they don't understand and fear they can't control. They worry that patrons with DD might be disruptive, destroy materials or library property, be loud, have a meltdown, or violate societal norms of personal distance.

While we tend to associate disruptive behavior with patrons with disabilities, library patrons without disabilities are capable of destructive or disruptive behavior, and in almost all cases, the unexpected behaviors manifested by people with DD are no different. The fear of possible behaviors may even be more destructive than the behaviors themselves if it causes librarians to steer clear of these people or treat them differently from other library users.

Librarians who program for adults with DD report that potentially upsetting behaviors are rare and easily handled. For example, the Arapahoe Libraries staff who run the New Day Storytime for adults note:

## Chapter 1: Perception and Self-Perception

As fun as storytime can be, there are occasional jarring incidents. At one time . . . a staff member had her hair pulled by a client. . . . While this doesn't frequently happen, such experiences teach us to pay special attention to the clients involved that day. When so and so is here, you learn to put your hair up into a ponytail.<sup>5</sup>

Understanding what behavior really is can ease concerns. Seen from the outside, unexpected behavior can seem random, but there is generally a reason for it. Behavior is a brain-based response to stimuli. It can be a form of communication, a way of self-regulating, a result of confusion, or a response to pain. Whatever else it is, unexpected behavior is not meaningless. One way of thinking about it is the ABC method. Every action has an antecedent, *A*, something that sets it in motion or triggers it. *B* is the behavior itself, and *C* is the consequence of the behavior. If the behavior gets us what we want, it is successful, and we will use it again. If not, most people will try a different strategy. In the case of the hair puller, the patron might have just wondered what the librarian's long hair felt like and not had the ability to understand that it is not socially acceptable to touch other people in this way.

A type of behavior that is often misunderstood by others is the stim or self-stimulatory behavior. Stims are repetitive behaviors, and many people do them, although they are most commonly associated with autistic people. Autistic stims include hand flapping, spinning or rocking the body, and spinning or lining up objects. However, if you twirl your hair while you read, click a pen over and over, or doodle, you too are stimming.

Some who work with autistic people feel that stims are bad, that they kept autistic people from focusing, are disruptive, and will cause other people to reject them. Their goal is to control stims through treatment, an application of the medical model that seeks to fix something that is inherently part of a disability. But autistic self-advocates have pushed back against the notion that stims are bad, and some experts have come to acknowledge that they have a positive function. For sensory seekers, stims can be arousing and stimulate endorphins; for sensory avoiders, they can be soothing and calming. They can help autistic people regulate their sensory systems and prevent meltdowns. Beyond asserting that stims are natural to them, autistic individuals describe stims as pleasurable. For example, Cynthia Kim reports:

Last night . . . I found myself twirling in the kitchen and instead of stopping, I let myself enjoy it. I kicked out my foot and made a full spin to the right, then kicked out my other foot and twirled to the left. I did it again and again and soon I found myself laughing out loud. Twirling around in the kitchen feels good. It feels right.<sup>6</sup>

Other common autistic behaviors are equally misunderstood, and in a series of tweets, Steve Asbell, who is autistic, explains what some of these mean: “What LOOKS like ‘stubbornness’ in an autistic is really ‘an innate need to understand the request and its reason’ before unnecessarily expending precious mental resources, wasting time and possibly subjecting ourselves to sensory and emotional overload.”<sup>7</sup> He goes on to say that what others see as “unusual and restricted interests” is really a manifestation of passion about a topic. What appears as aloofness is really an inability to understand and to please others. Perceived laziness is really a mix of anxiety, overwhelm, executive functioning disorder, and a lack of coping mechanisms and supports. And so on. As we said, behavior always has a meaning.

Once we understand what behaviors really are, it becomes easier to lose our concern about them and to provide for them as we program. If a behavior is loud but not harmful in any way, we can cheerfully provide a safe space where the person with a disability can practice it. We can be welcoming and understanding instead of fearful and dismissive.

### TIPS FOR WELCOMING ADULTS WITH DD

- Set clear behavior policies but be flexible.
- Manage expectations.
- Communicate effectively.
- Utilize natural supports like family members or caregivers.
- Provide a supportive physical and sensory environment.
- Ask people with DD what they need.

## CHOOSING WORDS CAREFULLY

Terminology that describes the disability experience is another thing, like disability models, that evolves over time. For instance, *mentally retarded* was actually coined as a less offensive replacement for earlier terms like *moron* and *idiot* that were used to describe people with cognitive impairments. Now, *mentally retarded* and its derivative *retard* are considered dehumanizing and offensive and the accepted term is the name of the condition, *intellectual disability*.



### Dated and Offensive Language

It is interesting to note that many of the outmoded terms are routinely used as insults against people without a disability or to describe ourselves if we make a mistake or forget something. How many of us call ourselves an idiot or say we are stupid under those circumstances, without thinking twice about what those words actually mean? Using these labels in this casual way is a microaggression, in the same way that using racist terminology would be. Imagine being a person with an intellectual disability overhearing someone use offensive words that describe your life experience as a casual insult. In language, as in other areas, institutional ableism runs deep. Author and editor Eric Michael Garcia described how he had to work at breaking this pattern in his own speech:

I've tried to stop using the words "moron" and "idiot." Hell, I've even tried to stop using the word "crazy" and what surprises me is how common these terms are and how often I am at a loss for an alternative because they are so ingrained in our language.<sup>8</sup>

It may be hard to find alternative words, but it is important to try.

At the other extreme are words that people might intend to be positive but are essentially condescending and insulting. *Inspirational* and *special* fall in this category. Harilyn Russo, a disability rights activist and psychologist with cerebral palsy describes how she feels when told she is an inspiration:

Well, frankly, I'm not an inspiration. I'm damn boring, if you ask me, which you rarely do. I worry about paying the rent, eating too much chocolate, and finding telltale wrinkles—sound inspirational yet? . . . I know, I know, if you were me, you'd never leave your house and maybe even kill yourself. So, I am inspirational because I haven't committed suicide—yet.<sup>9</sup>

A video created for World Down Syndrome Day in 2017 makes the case against the widely used term *special needs*.<sup>10</sup> A woman with Down syndrome narrates as actors demonstrate a series of truly special needs like having to eat dinosaur eggs, wear a suit of armor, or be massaged by a cat. The video points out that education, jobs, opportunities, friends, and love, the things that people with Down syndrome or other disabilities really need, are not special; they are what everyone needs.

Terminology can be confusing and even a bit hard to keep up with. However, an effort to understand what the terms mean and to use the ones that are currently

### BEST PRACTICES FOR TERMINOLOGY

Stick with person-first or identity-first language and avoid these offensive terms:

- afflicted with
- defective or birth defect
- differently abled
- exceptional
- handicapped
- high functioning/low functioning
- mentally retarded or retard
- spastic or spaz
- special needs
- has Down's
- crippled
- inspirational

accepted is an indication of our willingness to value the humanity and dignity of people with DD.

### Person-First or Identity-First Language

Another source of linguistic confusion in relation to people with disabilities is the choice between person- and identity-first language. Since the 1970s person-first language (PFL) has been the standard, based on the understanding that a person is made up of more than their disability. For example, someone is a *person with a disability*, not a *disabled person*.

For some self-advocates, however, disability is a matter of identity and pride and they see PFL as a negation of a basic fact of their existence. These people refer to themselves as *disabled* or as *autistic*, if their diagnosis is autism, and they may not like it when people tell them they need to use person-first language. In a series of tweets, self-advocate Emily Paige Ballou scolds professionals who call out people for using identity-first language:

I know you were taught that person-first language . . . is always correct. . . . I KNOW you mean well when you . . . snap at someone to use person-first language. But the problem is you've been taught out of date information, and as a result you're often just snapping at disabled people who are using language natural to our communities.<sup>11</sup>

A preference for person-first or identity-first language can vary from person to person and group to group. Parents of children with disabilities and the intellectual disability community often prefer person-first language; persons who are d/Deaf or hard of hearing and autistic people often prefer identity-first language. Like we

said, this matter of terminology can be confusing, but it is important to use the terminology the individual with the disability prefers, as Ballou suggests. When you don't know, starting with person-first language will convey respect and your willingness to get it right.

### THE NEURODIVERSITY MOVEMENT

The neurodiversity movement posits another way of looking at people with DD. It is based on the idea that peoples' brains are all wired differently, and a wide variety of neurological conditions are naturally occurring. The goal of neurodiversity advocates is to provide systems of support that allow people who are neurodiverse to be who they are and to live their best lives as themselves without a need to fit someone else's idea of normal.

Autistic people who are part of this movement embrace the social model of disability and use the neurodiversity spectrum-colored infinity symbol. They find the puzzle piece, historically used to identify organizations and products for people with autism, outmoded and offensive with its implication that people with autism are either impossible to figure out or deficient in some way. Using blue during April, as promoted by a controversial autism organization, also does not represent the feelings of many autistic people. Jess Benham, an autistic teaching fellow at the University of Pittsburgh and director of development for the Pittsburgh Center for Autistic Advocacy (PCAA), says this about what people with autism prefer:

I'm tired of politicians "lighting it up for blue" for a day or for the month, then not listening when I'm in their offices advocating for the issues that impact our lives. Autistic people need seats at the table where decisions are being made about us, not a month in which public figures and Autism organizations highlight negative stereotypes.<sup>12</sup>

Journalist Jessica Semler elaborates

A common theme when talking to actual autistic folks about this month is that they'd much prefer "Autism Acceptance" or "Appreciation Month." "Awareness" is a word we use to talk about negative things like sexual assault, domestic violence, cancer and other diseases. We shouldn't be talking about neurodivergent people like this.<sup>13</sup>

So, reconsider the color blue and the puzzle pieces on prominent display in April for Autism Awareness Month. Instead, highlight acceptance all year and

include self-advocates. Take a page from the Charleston (SC) County Public Library, which hosts panels of autistic people they call “Ask an Aspie,” as part of their Human Library program series. Started by author and consultant Tori Boucher in 2017, “Ask an Aspie” has continued because of strong positive community response.<sup>14</sup> Or follow the lead of Jennifer Murphy of the Palms–Rancho Park Branch Library, part of the Los Angeles Public Library (LAPL) system, and host an Autism Awareness Workshop. Theirs was sponsored by two local agencies and led by a panel of autistic teens and young adults. The session consisted of interactive presentations and time for discussion, and the event flier described it in this way: “You will hear insights about autism and get tips on how you can help individuals with Autism feel more a part of your local community.”<sup>15</sup> This is a worthy goal for any library program.

### NOTES

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13. Ibid.
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15. Palms–Rancho Park Branch Library, LAPL, Autism Awareness Workshop event flier provided by Librarian Jennifer Murphy, February 10, 2020.

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