Building inclusive communities: teens with disabilities in libraries

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Abstract

Purpose – This paper aims to provide concrete best practices to frontlines young adult and teen librarians for building positive, effective and welcoming relationships with young adults with disabilities at the library. The scope of this paper will include customer service strategies for working with young adults with disabilities. It will also feature strategies for making existing teen programming more accessible to young adults with disabilities.

Design/methodology/approach – By using the author’s professional library experience and citing other published works, this paper will present customer service strategies for librarians and library staff. It will share strategies for leading programs for and with teens with disabilities and will also address working with parents and caregivers of teens with disabilities.

Findings – This paper recommends specific strategies, so teen librarians are better equipped to provide inclusive customer service to teens with disabilities in libraries. These strategies are as follows: speak directly to the teen, consider communication and language, develop a rapport, respect their privacy, respect and encourage independence, think person-centered, invite their input, invite them to programs, be their advocate and give them permission to be teens. In addition, this paper shares various techniques for working with parents and caregivers, as developing positive relationships with parents is integral to cultivating positive relationships with teens.

Originality/value – Because of teen’s unique developmental, social and emotional needs, librarians require a specific set of competencies for positive engagement. Unless librarians have a background in accessibility or experience with someone with disabilities, they are inadequately prepared to address the needs of this population, specifically regarding customer service to teens with disabilities. This paper aims to build capacity of librarians by expanding knowledge and skills for working with teens with disabilities. As a result, librarians will be able to increase their competency and be equipped with concrete customer service tools. Librarians will be motivated to improve the accessibility of their libraries.

Keywords Customer service, Youth, Young people, Disabilities, Accessibility, Disability

Paper type Viewpoint

Library service to young adults is arguably one of the most challenging concentrations of librarianship. Because of teens’ unique cognitive, developmental, social and emotional changes and stages, librarians require a specific set of competencies, knowledge, and interpersonal skills to effectively engage with them. Not only must librarians possess these qualities, the success they have in serving this audience depends almost entirely on their ability to cultivate and maintain trust. Librarians need to be staunch and enthusiastic youth advocates to help their organization and community understand the value and importance of serving teens in libraries.

Young adult librarianship includes, though not always explicitly, service to diverse populations. In recent years, conversations of racial equity and LGBTQIA inclusion have dominated the diversity discussion in teen librarianship. One group that often gets overlooked in this discussion is teens with disabilities. I would argue that in order for a public library to develop a truly comprehensive outreach plan for diverse teens in their communities, the needs of young adults with disabilities must be addressed.
Teen librarians should have a strong foundation in their understanding of young adult development. Therefore, librarians working with young adults with disabilities require an understanding of how the disability experience affects the life of a teenager. Librarians also require competence in a variety of other disability-related areas as well. To communicate positively and effectively with their audience, librarians should have concrete knowledge of developmental needs, an appreciation of diversity, an understanding of disabilities, strong interpersonal skills, inclusive customer service abilities and good judgment. But do frontlines young adult librarians possess this knowledge and are they adequately prepared for this work? If not, how could they be providing equitable service in their libraries?

As the leading organization in our profession, the American Library Association provides guidance in the form of standards to prepare twenty-first-century librarians. Reviewing the current standards from the American Library Association (ALA) for ALA-accredited schools, it is clear that, unfortunately, no such curriculum or programmatic standard regarding the topic of accessibility or inclusion of people with disabilities exists (ala.org). However, the recently revised YALSA Teen Competencies aim to address this topic. Their competencies state that “taking into consideration cultural differences and special needs affords library staff the opportunity to create experiences that reflect the developmental needs of the teens in their specific community” (YALSA). Even between these two esteemed library organizations, there is no agreed upon standard or expectation related to serving teens with disabilities.

Operating independently from the American Library Association, the Edge Initiative goes further in their recommendations. Developed by a national coalition of leading library and local government organizations and funded by the Bill and Melinda Gates Foundation, Edge sets forth specific staff benchmarks in the area of staff training and learning. According to Edge, “staff [should be] provided with training at least annually for recognizing and serving patrons with disabilities” (libraryedge.org). Unfortunately, regardless of how pivotal its leadership and influence is on the profession, the Edge Initiative is merely a guideline for libraries. It lacks specificity in topics for training and does not address concrete learning outcomes. Ultimately, employers can choose to adopt this guideline and provide training—or not.

Without foundational knowledge in disability awareness, librarians cannot adequately address the needs of teens with disabilities. As a result, new librarians are unprepared and ill equipped to work frontlines and effectively serve this special population. Without proper and annual training, even seasoned librarians lack the knowledge and skills needed to work with teens with disabilities.

Without a firm understanding of what disability is or strategies for inclusive customer service, librarians could allow fear to influence their behavior, which could result in their reluctance or obstinacy. Fear of saying or doing the wrong thing can debilitate library staff from providing effective customer service. This can be particularly true for those who want to serve teens with disabilities, but do not know how. This fear creates a wall between librarians and teens, which ultimately prevents young adults from being authentically heard and seen as contributing members of their communities. But as Katie Mitchell writes in her article *Making the Wheel Bigger: Programming for Teens with Special Needs*, “It’s easy [for librarians] to get bogged down in the […] myriad of challenges developmental and cognitive disabilities present, but a solid base of understanding will go a long way for librarians and other staff members in knowing what to expect from patrons with these special needs” (Mitchell, 323).

Without proper guidance or direction, librarians are on their own to advocate for their learning needs in serving teens with disabilities. Having spent 11 years in public libraries
across the Midwest, I have had to rely mostly on those outside the profession to support my learning. I have learned from special education teachers, disability advocates, therapists, medical and health professionals, assistive technology experts, parents and caregivers and, most importantly, individuals with disabilities of all ages. I have worked with middle and high school special education teachers, observing their classrooms and co-developing programs to support curriculum needs. I have developed programs in partnership with disability related community organizations and social service agencies serving youth with autism and other disabilities. Leveraging partnerships with schools and with county departments, I have created community assessment tools to gather qualitative and quantitative data from the disability community, specifically from parents and caregivers, to align library work with school district and county priorities.

Unfortunately, my graduate school library and information science program did not adequately prepare me for serving people with disabilities. Without relevant coursework on inclusion and accessibility, on-the-job learning was essential and the only option for me. Even now, many newly degreed librarians must seek out disability experts and advocates outside the library field to fill gaps in their knowledge and experience.

Another gap that exists is the void in empirical and evidence-based research on this topic. Jo Kaeding’s article “Public Libraries and Access for Children with Disabilities and their Families: A Proposed Inclusive Library Model” acts as one of few credible and authoritative sources to guide the profession. According to the librarian interviews she completed in her 2014 North American library tour, she concluded the main barrier to public library access for children with special needs and their families is “library staff attitudes and sensitivities” (Kaeding). As one interview participant explained:

It not so much that their needs are not being met but that they are not even being considered. Most people don’t even know how many people with disabilities there are in their communities or that children have disabilities (Kaeding).

She also cites a “lack of knowledge on how to address barriers” as the main issue preventing libraries from addressing barriers to access (Kaeding). Moreover, her findings identified “disability awareness training for all staff” as having the greatest potential impact to increase access to youth with disabilities (Kaeding). Kaeding’s article points definitively toward staff learning and training as the most significant factor to increasing the accessibility of libraries to youth with disabilities.

I would argue that librarians do not require a degree in special education or personal experience with disability to welcome teens with disabilities in the library. Even without the background or personal experience, librarians only need an open mind, a willingness to learn, and a worldview that both honored difference and sought to find commonality among people. With these qualities, librarians can seek to develop real authentic connections in their communities with young adults with disabilities.

Based on my professional experience, here is a list of my recommended practices for inclusive customer service to help librarians and staff members build more positive relationships with teens with disabilities in their communities.

**Break down barriers**

Teens with disabilities encounter unique barriers to library access. Here are some possible reasons why they may not be visiting libraries:

- *Life is different.* Teens with disabilities have busy schedules with regular medical appointments and therapy sessions afterschool or on the weekends.
• **Lack of transportation.** If teens rely on others for transportation, they may not always have someone available to take them to the library.

• **Additional support required.** Some teens require additional one-on-one support from parents, caregivers or health-care professionals. Types of support needed may include communication, behavioral, emotional or physical support.

• **Worry and fear.** Fear is a natural human emotion and may contribute to why teens do not visit libraries. It may be fear or anxiety because of a mental illness or previously negative experiences had at the library or another community space. Some may be worried about possible judgment by other patrons or library staff about their disability.

• **Outdated guidelines or policies.** Libraries may have inflexible procedures or policies that inhibit teens with disabilities from using certain areas of the library. Getting to know teens one-on-one is a more effective way to build relationships, rather than holding fast to inflexible or potentially inequitable policy.

Not all disabilities are visible and can be perceived just by looking. Invisible disabilities are physical, mental or neurological conditions, which are invisible to others. Autism spectrum disorder, mental illness, learning disabilities, chronic illnesses, fibromyalgia and epilepsy are all examples of invisible disabilities.

**Speak directly to the teen**

Teens who require additional behavioral, physical or emotional support may visit the library with an accompanying adult caregiver. Upon introducing themselves and beginning a conversation with these staff, librarians may find it easier or more efficient to direct communication to the adult caregiver. This can be true, especially, if the teen is non-verbal or appears to have speech difficulties. It is important to remember, however, that every person wants and needs to be seen and recognized for their individual personhood and humanity. Young adults who rely on assistive technologies, American Sign Language (ASL) interpretation, or the assistance of others for their daily communication needs may not always be noticed as an individual. For able-bodied individuals, being recognized as a unique person is a privilege that can be often taken for granted.

Instead of ignoring or circumventing the teen with disabilities, the best approach is to speak directly to them and look them in the eye, smile and welcome them. Make the attempt to communicate with them first to find out their informational needs. This shows them they are seen as an individual person. Remember, they are not their caregiver.

However, depending on the teen’s communication abilities, it may be necessary for the librarian to adjust their delivery. For example, staff may need to speak louder, speak slower, use gestures or write something down on a piece of paper to be understood. Additional assistance from the caregiver may be needed, but it should not be used as a first resort. These may be small and seemingly insignificant adjustments to one’s communication approach. In actuality, these are an expression of dignity.

**Consider communication and language**

Language is divisive. Regardless of whatever the intention may be, words can have a powerful impact on people’s emotions and feelings. In the disability community, there are two approaches to language that identify individuals with disabilities, and the conversation within the disability community is equally divided as to which is the best approach: Person First Language and Identity-First Language. Person First Language puts the person before the disability, so that the
disability is no longer the primary and defining characteristic of the person. For example, instead of saying “the disabled person,” supporters of Person First Language will say “the person with a disability.” Those who prefer Person First Language emphasize that the value and worthiness of the individual is more important than the disability. Therefore, Person First Language is viewed as more respectful of the person with disabilities.

Contrary to Person First Language, Identity First Language puts the disability first. For example, instead of saying “the person with autism,” proponents of Identity First Language would say “the autistic person.” People who subscribe to identity first language consider the disability as important part of who they are. It is seen as an integral part of who they are as a person and inseparable from their identity.

Because of these two schools of thought, it can be difficult to determine the appropriate strategy when working with a young adult with disabilities. A best practice is to ask the teens how they want to be called. Unfortunately, language is not one-size-fits all. Not every teen will agree on what words to use to describe their disability. Some teens may even shy away from having their disability disclosed. That is okay. Instead, what library staff should do is focus on the impact of their words, rather than only the intention behind them. A recommended starting point would be to ask the teen their name and ask them directly how they want to be called. The mere act of asking young adults and relying on their input demonstrates respect and shows them they are valued.

Develop a rapport
Another way for librarians to improve their service to young adults with disabilities is to get to know them in a respectful and authentic way. Librarians can find opportunities to connect about what teens enjoy – books, movies, TV shows, games, outdoor activities, music or sports. Librarians can ask questions about their day or their plans for the weekend. If open-ended questions produce anxiety or communication difficulties for the teen, librarians can consider rephrasing with yes or no questions or providing them with a limited selection of choices. Every teen is different; so in some cases, humor or jokes may be appropriate depending on their individual personality.

Having the opportunity to connect with an adult who is not their parent, teacher, doctor, therapist or caregiver is rare for teens with disabilities. Because of that, librarians are uniquely positioned to be positive adult role models and mentors. This could be a formative and important experience for teens with disabilities, which could have a positive impact on other aspects of their lives as well. This rapport can help decrease feelings of isolation and increase self-confidence and self-worth. Through simple conversation and positive relationship building, librarians can take the time to recognize the humanity in the teens they serve.

Respect their privacy
It is natural and developmentally appropriate for teens to desire increased amounts of privacy in their lives; the same holds true for teens with disabilities. For librarians, respecting privacy for young adults with disabilities in the context of libraries can mean a variety of things. First, librarians should be cautious about the issue of outing when working with teens with invisible disabilities, such as autism spectrum disorder, learning disabilities, health issues or mental illness. Disclosing a teen’s disability to others without their prior knowledge or permission should be avoided at all costs. Information about their disability should be disclosed by the teen and only the teen, and librarians should respect the right to privacy in this area. In addition, teens with invisible disabilities may not want to have others know about their disability. Therefore, outing a teen’s disability without their permission can be upsetting, even traumatic.
Librarians also want to ensure that teens have access and ensure that their informational needs are met. This includes information about their development and disability. As Carrie Banks says in her book, *Including Families of Children with Special Needs*, “In the library, privacy and confidentiality come into play more. Young teens may want information on homosexuality or birth control or careers that their parents are not considering for them. They may want more information on their disability or may distance themselves from it” (Banks, 47). Librarians should focus on the expressed need, so that they can provide them with excellent library service. However, librarians should remain conscious not to cross the line, which may be different for everyone, with regard to their privacy and what that teen feels comfortable sharing. If it is difficult to discern or assess the information need of a young adult with disabilities for reasons such as communication differences or self-consciousness, Carrie Banks recommends the following questions:

**Q1.** To determine the preferred format, “Do you read with your eyes, ears, or fingers?”

**Q2.** To determine the preferred reading level, “What was the last book you read and liked?”

**Q3.** To avoid stigma, “Do you want help with that?” as opposed to “Do you need help with that?” (Banks, 110).

No matter the ability or disability, young adults are trying to navigate a multitude of new and complicated social interactions. A right to privacy is crucial to support their development.

**Respect and encourage independence**

Learning to separate from their parents is an important developmental step, so it is natural for teens with disabilities to desire independence as well. For these teens, however, it is possible that some may never have the opportunity to live a completely independent life. There are some young adults with disabilities who may always have a parent, caregiver or nurse providing them with some type of support for the rest of their lives. But no matter what level of independence teens with disabilities achieve in their adult years, their adolescence is the perfect time to experience a new sense of freedom and build life skills.

Libraries and librarians can support teens with disabilities in skill building and independence in a myriad of ways. As Katie Mitchell states, “It’s important to acknowledge the strengths of [young adults with disabilities] and support the ultimate goals of developing relationships, self-help skills, and the highest level of independence possible” (Mitchell, 323). If independence is the ultimate goal, attending library programs independently without the support or supervision of their parent or adult caregiver is one way teens can begin to achieve that goal. Attending programs with others in their peer group gives teens with disabilities more autonomy to socialize, learn from others, make decisions, and – just as importantly – make mistakes in a safe, supportive environment. These experiences can lead to learning and growth, which may ultimately inform some form of decision-making later in their lives.

Independence also includes the freedom to choose. Libraries can support a young adult’s need for independence by letting him or her make their own choices about what information they want to access at the library. The ability to select items that appeal to their own interests and hobbies, rather than having others do the work for them, encourages teens to develop their own sense of identity. As Carrie Banks states in *Including Families of Children with Special Needs*, “The library can support the teens’ need for independence by offering the information that they need in a format that is accessible to them.” She continues saying that
“Requiring teens to use their own library cards, regardless of their grasp of the finer points of the privilege, can support these needs. Providing volunteer [and program] opportunities for teens with and without disabilities is another way to support teens’ need for autonomy” (Banks, 46-48). With this lens, librarians can consider the entire experience of visiting a library and using its services as an opportunity to build and practice those skills for teens with disabilities.

Think person centered

Rather than focusing on what libraries can do for teens with disabilities, librarians should adjust their perception and think person centered instead. So, often libraries focus on their needs or the services they provide others, but what person-centered planning does is refocus to what works for the teen as the primary concern. The PACER Center in the state of Minnesota works to do just that.

An organization that works to enhance the quality of life and expand opportunities for children, youth, and young adults with all disabilities and their families, PACER allows each individual to reach his or her highest potential through person-centered planning. According to PACER’s National Parent Center for Transition and Employment, person-centered planning is defined as “an ongoing problem-solving process used to help people with disabilities plan for their future. In person-centered planning, groups of people focus on an individual and that person’s vision of what they would like to do in the future. This team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives and develop the skills and abilities needed to achieve these goals” (pacer.org). Person-centered planning can be used in various aspects of the lifespan for a person with disabilities, but it also has application for libraries as well.

Libraries that involve teens with disabilities in their volunteer programs or as paid staff members are prime candidates for adopting person-centered planning. Libraries may develop their own list of tasks and projects that need to be completed by teen volunteer or staff member. However, if the young adult finds these tasks unfulfilling, if the projects are mismatched with their skills or there is a mismatch between their interests and the activities, it is unlikely the experience will be successful or positive. In teen volunteer programs, for example, librarians should first assess their teens for their interests, skills and strengths. Librarians can think about how the volunteer experience can be mutually beneficial for the teen and the library. Involve parents, teachers and the young adults with disabilities in the brainstorming and planning process to ensure that all needs are met. If a teen volunteer has been a part of the process in developing the plan, this gives the teen with disabilities ownership over their role.

Everyone has the right to contribute and belong to a community, and the library can be the heart of the community where everyone's contributions are valued and recognized. In a School Library Journal article entitled Almost Adult with Autism, author Carly Okyle discusses the work of Kohli Mathur, CEO and cofounder of Spectrum Success. Okyle reports, “Mathur’s service helps older adolescents transition from school to the workforce by conducting a behavior evaluation and then creating a personal program to address behaviors and provide training for a job that interests the client. Libraries can partner with vocational programs by inviting individuals with [autism spectrum disorder] to work—either for pay or as a volunteer” (Okyle). Mathur’s workforce program is an excellent example of person-centered design in that each job is customized to fit the client, rather than fitting the client to match the job.
Invite their input

When a person is asked to contribute their thoughts and opinions about a new process or service, it can help to increase the amount of buy-in that person has about that process or service. It is also true that if teens with disabilities are intentionally included and asked to give their feedback about something, they would most likely have more ownership about it.

As Kowalsky and Woodruff write in their article *Creating Inclusive Library Environments: Plans for Serving Patrons with Disabilities*, “People with disabilities will expect library staff to have the same expectations of them as they do for other patrons. It is important to ask individuals with disabilities for feedback on specific ways to meet these universal expectations” (Kowalsky). One aspect of library service especially worthy of feedback from a young adult with disabilities is staff training. As Kowalsky and Woodruff suggest, “Regular library users with disabilities can provide their opinions on what should be covered in staff training. Recurring issues may be identified, such as complaints about time spent standing in line or carrying items or not being able to find an available seat in a reading area or computer station. Round-table meetings or online group discussions can let patrons offer feedback about using the library through the lens of their disabilities. They should be encouraged to report situations that prompted them to feel embarrassed or guilty when interacting with others or disappointed or angry when people have patronized them or were insensitive to their needs” (Kowalsky).

Young adults with disabilities have the life experience and the perspective of a person with disabilities, but they are also at a stage in their development when they are beginning to form their own opinions and express themselves. By involving young adults with disabilities in the planning process to develop inclusive staff training, for example, the library achieves several things:

- Young adults with disabilities are heard and validated for their opinions.
- The library receives authentic feedback from a diverse user group in their community.
- Young adults with disabilities are co-planners of a training program for library staff.
- The library develops relevant training program that has a positive impact on the community.

Teens with disabilities can contribute to much more than staff training, however. In Carrie Banks' book, *Including Families of Children with Special Needs*, she recommends librarians involve teens with disabilities in the evaluation process and assessment of staff attitudes, the physical library space, materials and resources to ensure that it meets their needs (Banks, 115). Ultimately, the responsibility lays with librarians who need to know when and how to ask for feedback about library programs and services, and what to do with that feedback once it is gathered. The simple act of asking a question could be a powerful way for librarians to build a positive and trusting relationship with a young adult with disabilities in their communities.

Invite them to programs

Programming is essential to young adult librarianship and it is one of the most effective ways to meet and build a rapport with teens in the community. For teens with disabilities, library programs can be an extremely positive experience – not necessarily because of information learned or skills developed, but rather the sense of belonging that is felt by
those who attend. As Megan Cottrell reports in her article entitled *Aging Out of Sensory Storytime*, “A 2012 study in Pediatrics found that after leaving high school, young adults on the spectrum were three times more likely to be disengaged from the community and work, compared with people with serious mental illness or cognitive disabilities” (Cottrell). Because teens with disabilities experience feelings of isolation and disconnection compared to their typically developing peers, library programming can help them see they are part of a community.

There are many reasons why librarians can and should program for teens with disabilities. Libraries can offer programs that address a variety of interest areas, including arts and crafts, technology, science, music, writing and gaming. As Leslie Lea Nord says in her article *Reaching Out: Library Services to the Developmentally Disabled*, “[Teens] with these disabilities commonly have limited options for educational opportunities once they become adults. Options for other stimulating daytime activities can be expensive or have long waiting lists. Often it is the television that becomes their [only] source for education and intellectual stimulation” (Nord). Libraries who welcome teens with disabilities in programming are providing safe spaces for them to gather and explore their own interests – all for free.

Encouraging teens with disabilities to attend library programs is not only a way to build rapport it also improves outcomes for these young adults as well. Here are additional positive outcomes when teens attend library programs, they:

- cultivate a sense of independence;
- practice life skills;
- learn to make friends;
- have opportunities for experiential learning;
- are exposed to literacy and books;
- learn about the library as a lifelong resource;
- learn from their developing peers;
- practice their communication skills;
- express themselves;
- explore their interests;
- experience a sense of belonging; and
- are visible as participatory members of the community.

**Design programs for teens with disabilities**

For libraries looking to develop innovative programming ideas for teens with disabilities, here are some suggestions:

- *Book clubs*. Next Chapter Book Club connects teens and adults with intellectual disabilities at all reading levels. Members come together to read together, talk about books and make friends in a community setting. Librarians and community volunteers facilitate the program.

- *Homework help*. According to the National Center for Educational Statistics, high school graduation rates for students with disabilities are roughly 20 per cent lower than the national average (Grindal and Schifter). To address this gap, connect with the school district and demonstrate library online homework help
resources to students, special education teachers, and counselors. Offer an afterschool tutoring program for youth and promote it to teens with disabilities. Provide workshops about executive functioning to support teens in developing school readiness skills.

- **Job programs.** Work with special education teachers to create a program about job and career skills. Explore different career options through books or movies or teach students how to build a resume. Bring in a guest speaker to discuss creating vocational portfolios or use digital media technology to create a video resume.

- **Sensory-friendly movies.** Traditional movie-going experiences are not always accessible for teens with disabilities. Sensory-friendly movies show the movie with the sound down, lights up and closed captions on. The environment is supportive for moviegoers who need to move and make sounds.

- **Social clubs.** Social clubs can support young adults with autism or other disabilities by decreasing isolation from the community. Teens can come together to share common interests, develop new skills, or find academic support.

- **School visits.** Transportation to the library could be a barrier for some students. Instead, bring programming into the classroom. Work with teachers to select a storytime theme that aligns with curriculum. Show pictures or videos of the library to help teens know what to expect during visits. Consider off-site library card registration during parent/teacher conferences or school events.

### Include and accommodate teens with disabilities

Librarians do not need to develop new programs to serve young adults with disabilities. In fact, teens may not want to be stigmatized in a separate program. Instead, here are some strategies to apply to existing teen programs to make them more inclusive for teens of all abilities:

- turn on closed captioning during movie programs to support deaf teens or teens with hearing loss;
- offer ASL translation services during the program or utilize a local volunteer fluent in ASL to translate during the program;
- magnify activities or stories using a projector and screen; adjust the brightness and size as needed;
- use visual schedules and choice boards to support non-verbal or shy teens with making choices and following along with the program activities;
- purchase supports, such as noise canceling headphones, fidgets and assistive seating to support various physical needs;
- keep groups small or offer a peer as a buddy to provide assistance during the program;
- allow parents to stay if both the teen and the parent are comfortable and both understand their respective roles during the program;
- develop a Program Accommodation Form and make it available on the library’s website to gather information in advance regarding the teen’s interests, abilities, and needs;
• create a Social Story about what the teen can expect during the program or create a program outline; share the social story or the program outline in advance with both the teen and the parent; and
• e-mail or call teens ahead of time to ask about additional support needs.

Be their advocate

One of the most important roles librarians assume is advocate. A young adult with disabilities needs a profound amount of advocacy in their lives. From their parents or guardians, to their teachers and health-care providers, every adult in their life advocates for various aspects of that teen’s needs.

Librarians, too, can advocate for the needs of teens with disabilities. Whether it is advocacy for information or independence, librarians understand that teens, regardless of their disability, both support and space to navigate their world. Parents of teens with disabilities, for example, may worry and struggle when their child expresses a newfound desire for independence. Consequently, these parents may want to attend library programs along with their teen with disabilities. This may be especially tricky to navigate if parents are also the child’s caregiver, support provider and teacher.

In this situation, librarians can advocate for the teen with disabilities by engaging with the parent or caregiver in conversation. Explain the benefits of independence as a life skill – that is necessary for all teens to experience and develop in their adolescence. A library could be a safe environment for that teen to experience this freedom for the first time. To help ease parental anxiety, librarians can ask the parent questions to find out more about the teen prior to the program. Librarians could also share a list of program activities, so that both the teen and the parent know what to expect. If the parent is also the teen’s primary caregiver, they may not often have ample free time. Therefore, if appropriate, librarians can gently encourage the parent visit other areas of the library and enjoy their free time.

Because being an advocate means active listening, if that same teen asks for their parent or caregiver to attend the program with them, respect and support their choice.

Give them permission to be teens

It does not matter if young adults have a disability or not; teens deserve validation and respect from all adults in their lives. What that means for adults is accepting the variability that exists with young adult development. Teens have both good days and bad days. Teens want to be recognized for their contributions and want to be given space and left alone. They want freedom to make their own decisions, and support when they make mistakes. Teens can be misunderstood, ostracized, bullied, or bully others. Teens may want to belong to a group to blend in, but may also be learning about what makes them unique.

In addition, adolescents experience a plethora of emotional, personal and social changes in a short time span of their development. In Chapter 3 of Carrie Banks’ book, Including Families of Children with Special Needs, she identifies a variety of aspects of the development of young adults between the ages 14 and 17:

• sexual identity established; sexual activity develops;
• sense of identity develops; ethics get more nuanced; comprehension of abstract concepts increases;
• academic differentiation continues to increase; vocational tracking may occur;
• risk-taking behaviors may increase; decision-making skills develop less rapidly;
logic becomes more secure; vocabulary deepens and broadens; and

awareness of larger world issues grows and takes on importance (Banks, 35).

In the life of a teenager, the only constant is change. At the same time, teenagers are trying to make sense of the world around them, while simultaneously trying to figure out their place in it. How, then, can librarians support teens with disabilities in this stage of self-discovery?

One strategy is to advocate for developmentally appropriate library programs and services that focus on peer-to-peer relationships for teens with disabilities. It is common for librarians to hear parents of young adults with disabilities say “My son is seventeen years old, but has the mind of a four year old. So, I would like him to attend preschool storytime.” What librarians can interpret from this statement is that the young man has an intellectual or cognitive disability. However, librarians should use caution when drawing conclusions from phrases like these.

There are other factors that should be taken into consideration. For example, will he be supervised by a caregiver during the program? Do any of the storytime activities, such as music or movie, trigger anxiety or potentially destructive behavior? Has he been around other young children before in a similar setting? In cases like this, librarians should use their best judgment when deciding if it is appropriate for young adults with disabilities to attend programs with other young children. As an alternative, consider offering a story hour program for teens that features picture book readalouds. This program allows teens to develop peer-to-peer relationships with other young adults in a setting that is appropriate for their interests as well as their development.

Support parents of teens with disabilities

A crucial part of building positive relationships with teens with disabilities is building a positive relationship with the parent. Parents and guardians play a crucial role in any child’s life. Their care and love for their child with disabilities may often come in the form of steadfast advocacy speaking out to ensure that their child has the same access and opportunity as everyone else. Ultimately, just like any parent, they want what is best for their child.

In many cases, parents of young adults with disabilities may also be one-on-one caregivers. These parents may act as homeschool teachers supervising educational requirements. They may attend to their child’s physical needs, and may be providing daily transportation to and from appointments. When working with teens with disabilities in libraries, we should remember that the relationship between that teen and their parent is unique. Here are some effective strategies for building positive relationship with those parents:

- **Identify common goals.** Make sure that the librarian and the parent all share the same understanding regarding outcomes. Ask questions like “What do you hope your child will gain from this experience?” or “How can I support your child in the best way possible while they are here in the library?” Be sure to share information about specific objectives and goals the library has as well. Whether it involves employment, volunteering, participating in a library program or visiting the library independently, there should be open communication between the librarian and the parent.

- **Remain flexible.** Librarians are nothing if not flexible, and flexibility is an asset when working with parents of teens with disabilities. For example, if the library
offers a program for teens to attend independently, but the parent wants to observe
the program, librarians can consider allowing the parent to stay and watch.
However, librarians would also want to respect the feelings of the other teens in the
program. Having an adult in a teen program changes the dynamic drastically, and
not always for the better. Consider having a conversation with the parent ahead of
time to share the librarian’s goals for the teens’ experiences during the program and
what role the librarian wants the parent to play.

- **It is okay to push.** It may be a struggle for parents to go outside of their comfort zone
  and try something new. This can sometimes be true for parents of young adults
  with disabilities who are having difficulty being flexible or compromising.
  Librarians should not be afraid to advocate for the needs of the teen, especially if
  they think the teen’s voice is not adequately being heard by the parent. This may
  come up with regard to a teen wanting to exert their own independence from their
caregiver. Always be kind and considerate when making suggestions that may be
difficult for the parent to hear.

- **Refrain from judgment.** Librarians can sometimes be overly critical of choices that
caregivers make in their parenting styles. Negative perspectives and judgment from
a librarian acts as a barrier between patrons impeding their ability to have positive
interactions in the library. Especially with regard to parents of young adults with
disabilities, librarians should refrain from judgment. Library staff may not always
agree with a parenting decision, but they should respect parents enough to
remember they have the right to make that choice.

- **Provide credible information.** Parents of young adults with disabilities are inundated
by a tremendous amount of information regarding their teen – their disability,
school, medical needs, therapeutic needs, employment and lifelong care. Sometimes
parents themselves may not receive credible information, so it is the responsibility
of librarians to share that information. As Carrie Banks writes in her book *Including
Families with Children with Special Needs*, “There is a dearth of information for
parents on the development of teens with disabilities or their health care needs.
When formal resources are not available, libraries can link parents with other
parents in person or electronically to help meet these types of needs.” (Banks, 47)
Some parents may ask librarians to advise them regarding various topics. This is
not the role of library staff. However, what librarians can and should do is, to the
best of their ability, is provide information that parents need.

- **Offer family-centered programming options.** According to the 2016 publication
*Public Libraries: A Vital Space for Family Engagement*, research shows that youth
have improved outcomes when the entire family is involved: “Nurturing and
supportive families are important for children’s healthy development and positive
attitudes. Even into early adulthood, guidance and encouragement from family
members help shape young people’s attitude toward school, relationships, and life”
(Lopez). Practically speaking, family-centered programming allows parents and
caregivers flexibility to attend a library program together, rather than having to
arrange childcare for other children. This is especially important for parents of
young adults with disabilities who have other children. Everyone can enjoy the
experience together, including siblings and the whole family. As Mitchell writes,
“One of the greatest challenges for special needs families is finding a social
atmosphere that is welcoming to all their members” (Mitchell). Family centered
programming that is accessible to all ages and all abilities is the perfect solution for libraries.

- **Set appropriate boundaries.** Because of the daily stressors and challenges that may arise, sometimes parents with young adults with disabilities may be looking for one-on-one adult interaction, especially if they do not have a support network of adult peers. Parents may seek out conversations with librarians to socialize, ask advice or vent. At times, these interactions may go on for quite some time, inhibiting staff from being able to do their jobs effectively. It is best practice to be approachable and supportive within means. Staff should use their best judgment to establish a professional and collegial rapport with parents and caregivers. However, if at any time a parent crosses a line that is uncomfortable to staff, speak with a supervisor or management and ensure to establish appropriate limits for interaction.

- **Be empathetic.** Librarians never know what personal hardship a patron is going through when they visit the library. Considering all of the potential challenges that may arise from having a child with disabilities, parents and guardians may be experiencing profound levels of stress, fear, anxiety, depression, or exhaustion on a daily basis. Sometimes the most meaningful thing librarians can do for a parent of a young adult with disabilities is be patient and empathize with another human being experiencing a difficult moment in their life.

**Concluding thoughts**

Librarians are role models, advocates, mentors and positive adult figures in the lives of the young people they serve. Librarians understand that one-on-one connections or a simple conversation can have a profound impact on someone’s mood, the trajectory of their day or their lifelong success.

The same is true for teens with disabilities. Whether it is through customer service, programming, outreach or everyday conversations, librarians can provide these teens with a place in libraries. Through their actions and their words, librarians can recognize and validate these young adults for their interests, talents, strengths, and all of the qualities that make them a unique individual – not what makes them different. With compassion, dignity, trust, concrete tools and strategies, librarians can enhance the relationships they have with the teens in the library. And in turn, young adults with disabilities can find a place in the community where they are visible and where they belong.

**Further reading**


**About the author**

Renee Grassi is a leader in services for patrons with disabilities and was named a 2012 LJ Mover & Shaker for this work. She has implemented many library programs serving youth and adults with disabilities, presented at PLA and ALA Annual Conferences, ALSC Institute and guest lectured for the Graduate School of Information Studies at Dominican (IL) University. She co-founded SNAILS – a networking group dedicated to developing accessible libraries – and is a member of MELSA’s Inclusive Services Committee. Renee is Youth Services Manager at Dakota County (MN) Library and considers herself an ally working to make libraries accessible for all. Renee Grassi can be contacted at: renee.grassi@gmail.com