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Autism Spectrum Disorder

An Insider's Perspective in Public and Academic Libraries

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Abstract

This paper's purpose is to bring to light the social issue of Autism Spectrum Disorder (ASD) and how public and academic libraries are making strides to better serve this branch of the population. Definitions will be provided to better explain what challenges ASD patrons face. In turn, librarians across America, specifically in Illinois and Ohio in recent years, have come together to discuss in both literature and national forums what they are continually doing to better serve, educate, and support their patrons and train their librarians. ASD is a complex social issue faced by millions; one widely covered and not easily solved alone, but through strategic planning and partnerships, libraries are formulating some creative solutions to meet these challenges. Also touched on will be the perspectives of librarians with ASD; the challenges they face each day, and where they see the future for people with ASD working in a library setting. Let us discover how libraries are rising above these challenges and becoming better informed to equip one another to serve all their patrons.

Keywords: autism (ASD), Asperger's, librarians with ASD, accessibility, neurodiversity, patrons with ASD, learning disabilities

Autism Spectrum Disorder: An Insider's Perspective in Public and Academic Libraries

Introduction

There are many avenues to look at when examining the topic of ASD and how libraries are addressing people's needs. I was surprised in my research just how vast the number of resources there are to aid an individual with learning challenges. On a personal note, this topic hits home for me. With one sibling that falls into the autism category, this project has been an eye-opening experience for me on my journey to be a future librarian. In what ways are libraries succeeding and being challenged in meeting the needs of their autistic patrons and their fellow librarians? Public and academic libraries are playing a key role in educating, supporting, and offering programs, and various perspectives on the social issue of autism.

Definitions and Challenges

Various terms of ASD are circulated across our society. According to the National Institute of Mental Health (NIMH), "Autism is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave" (NIMH, 2022). Sarah Mears, Library Services Manager at the Essex County Council Library in the United Kingdom, would concur with this definition with a few slight differences. She illustrates that people with ASD may have "over or under-sensitivity to sensory stimulation, difficulties with organizing, sequencing and prioritizing; and have intense responses to overwhelming situations" (2017, para. 3). Furthermore, according to Adam Felman, writer for *Medical News Today*, Asperger's Syndrome is a type of autism characterized by social and communication difficulties and repetitive or restrictive patterns of behavior (2017). Many in the medical field categorize autism and Asperger's with similar characteristics. Only in recent years have these terms been umbrellaed under ASD. The challenges that arise for people facing ASD at times can be daunting. It is in these times that it is important to keep in mind that challenges can and do become strengths if perspectives are changed.

Strengths in the Midst of Challenges

These definitions and insights into the challenges facing people with ASD offer clarity to those who do not see these challenges up front. In what ways might these challenges become strengths? Many with ASD take on life in unique ways. According to Steven Zauderer, CEO of Cross River Therapy, "... having a favorable

opinion about autism can alter the way others see and interact with people that have the disorder, and how they respond” (Strengths and Benefits in Autism, 2022, para. 5). He illustrates in his article some positives of those with ASD. People with ASD have a keen attention to detail, concentrated focus, elevated levels of creativity, and new perspectives on learning. This is one perspective among the thousands that are showing how having ASD is not a sad thing, nor a limitation to someone but can have positive benefits.

Statistics

The statistics do not lie. Autism spectrum disorder (ASD) is a real issue. In a 2010 U.S. Census report, Suzanne Schriar, Targeting Autism Project Director at Illinois State Library indicated that, “more than 56 million people (close to 20% of the population) have a disability” (2019, p. 78). In addition, 1 in 68 births has been identified as having autism (Schriar et al., 2017). As of 2021, the Center for Disease Control and Prevention (CDC) released a report that the prevalence of ASD in the U.S. among children “aged 8 years per 1,000 was 23.0 and ranged from 16.5 in Missouri to 38.9 in California” (Maenner et al., 2021, para. 4). Thus, ASD prevalence among children has risen across the U.S. in the last decade. These sample statistics address only a small part of how prevalent ASD has become and the reality of what needs to be done. How are libraries across the United States responding to this issue?

National Discussion

Beginning in 2015 and 2016 in Illinois, two national forums were convened by the *Targeting Autism* initiative using grant funding from the Institute of Museum and Library Services (IMLS) to address the issue of ASD. “Librarians, service providers, teachers, and self-advocates” were in attendance (Schriar et al., 2019, p. 80). Four points were discussed, which gave participants:

a basic understanding of autism... the role of libraries in serving autistic individuals and family members... expertise and resources... [and] multi-stakeholder collaboration in the design of programming and services to increase the value and use of libraries with the autism community. (Schriar et al., 2019, p. 80)

The main takeaways of these forums were to bring awareness to the issue of autism, discover ways to better serve autistic individuals, and initiate community collaborations with multiple organizations to design and increase the services and programming provided to the autism community. Furthermore, what was also

learned is that there is a need for more “support groups, proliferation of inclusive spaces, intern programs at libraries for autistic residents, assistive technology training in libraries, and more use of social stories” (Schriar et al., 2019, pp. 80-81). Raising awareness of what can specifically be done by libraries and the community for autistic individuals can go a long way to begin to show autistic individuals that they are not alone and that there are people who care making a difference in their lives too. What strategies are being used by libraries nationwide to help those with ASD?

Project Achievements by Libraries Nationwide

Sensory Strategies to Provide Stimulation to Participants with ASD

In places like the Louisville Public Library in Louisville, Ohio, the actions of a few librarians through the Discovery Center are making headway with patrons faced with special needs. Michael Damron, author of the article, “A Sensory Wonderland,” illustrates how this amazing idea came about and what it is doing for the community:

The idea came from two staff members who have children on the autism spectrum... The space is made up of two sections. One section is filled with tactile objects providing physical interaction, delighting those who are under-stimulated... These objects include an interactive balance beam, a musical vibration bench and touch-sensitive walls. The second section is a relaxation area designed to limit stimuli and full of soothing colors, dim lights, and optical illusions; targeting children with ADHD” (Damron, 2019, paras. 2-4).

The impact this program is having on others can be clearly seen. The program’s musical benefits for those with ASD are intriguing. The concept could be incorporated in other communities as well. Within the first week of being opened, over 1,000 people experienced the Discovery Center, and many continue to come. Adults and children alike are benefiting from the program’s musical stimulation. What other strategies are being used to reach patrons with ASD and train library staff to improve library spaces?

A Discussion on the Strategies and Training Library Staff are Receiving to Improve Library Space for Patrons with ASD

Across the United States, libraries continually work towards improving their library spaces for patrons with ASD. This is very evident in some of the creative IMLS-funded project solutions that came about because

of meaningful and intentional conversations at these national forums. One of these was Project Enable, created by Dr. Ruth Small and her team from the Center of Digital Literacy at Syracuse University:

[Project Enable] began as an initiative to provide in-depth training to school librarians on ways to provide appropriate and effective library information programs to serve students with disabilities. The need for wider distribution of this training resulted in the development of freely accessible online, self-paced training modules. Public and academic libraries are also targeted to receive training (Schriar et al., 2017, p. 6).

Efforts such as Project Enable in Illinois libraries are giving library staff the necessary training to equip them to understand, relate to, and serve those in the ASD community. There are a multitude of examples of project outreaches like this one that are making a real difference.

At the Chicago Public Library (CPL), community collaborations are making an impact on the ASD community. Working with the Autism Program of Illinois, CPL is taking the time to provide accessibility and support services training to their library staff to equip them to better serve the needs of an autistic child patron. One way this is being done is through accessibility kits. According to George Winson and Courtney Adams, authors of the article "Collaboration at its Best," accessibility kits will teach individuals with ASD "step-by-step... through pictures and brief descriptions... what to expect in all areas of the library, from story time to the circulation desk" (2010, p. 17). Children with autism can relate to visual pictures and simple, straightforward descriptions better than a book in small print with too many details that their short attention spans may not be able to grasp.

The stories of those with ASD and their family members are inspiring the experiences of those just beginning their journey to understand ASD. In developing their collections, librarians are placing book material on their shelves to which ASD patrons and others can relate. According to Martha J. Boman and Cynthia Houston of Western Kentucky University, in their article "Listen to Our Voices!" stories can "help us better to understand the culture, customs, and behaviors of those from the Autism Nation" (2015, p. 13). Each story selected, whether for children or adults, can make an impact. By telling the personalized stories of those who have ASD or live with those who do, we can better see and understand the person facing the trials and not just the disorder itself. For example, this can be echoed in *Carly's Voice: Breaking Through Autism* by Arthur

Fleischmann, *The Way I See It: A Personal Look at Autism and Asperger's* by Temple Grandin, (2011), and *Puzzled: 100 Pieces of Autism* by Nilla Childs (2012) (Boman and Houston, 2015, p. 13-14). Each of these stories examines the emotional and turbulent journeys of autistic people and those close to them. When we delve deeper into real stories like this, we can begin to foster a sense of respect, inclusivity, relatability, and understanding for the names and faces of individuals facing or living with autistic persons.

Environmental and Planning Considerations Being Incorporated by Libraries Nationwide

Seeing and experiencing a library's environment and programs for autistic individuals can be daunting and paralyzing. What is being done to change this? According to graduate student Kim Marsh Read in her article "Reflections..." two libraries in New Jersey are taking a hands-on approach by making environments "more welcoming" to children by incorporating "small quiet spaces with beanbag chairs and rocking chairs" which can produce a calming effect (2009, p. 14). Additional incorporations include "koosh balls, pipe cleaners and water bottles" (2009, p. 14). Keeping an autistic child's sensory needs in mind is a wonderful way to make them feel welcome. As far as programming, "story times geared towards autistic children should have clearly defined activities, commitment to a defined schedule... books with repetitive language, circle time, drawing and singing" (Read, 2009, p. 14). Having highly interactive activities and structured events for autistic children can only help to stimulate their interests and thought processes.

Elsewhere in New Jersey, Antonette K. D'Orazio, a children's librarian at Bernards Township Library, offers some excellent ideas for how story time with autistic children can be spent. What do these ideas entail? "Involve children as much as possible. Ask questions even if you think you will not get answers... Investing in props such as hand puppets or scarves will pull children into the program... Use rug squares on the floor to signal to children and parents where you want them to sit" (D'Orazio, 2007, p. 22). The incorporation of ideas like those mentioned for story time and developing a library environment are creative and highly engaging. Ideas like these are what ASD children and their parents can be a part of together, share memorable moments, and benefit as a result.

Tackling projects like those for people with ASD in Ohio, Illinois, and elsewhere requires time, planning, and a comprehensive strategy to implement. Several fundamental questions need to be asked and

areas considered. Let us consider what Renee Grassi of the Dakota County (Minnesota) Library System offers as a starting blueprint:

- Address the 'why' behind your decision to improve service to this population.
- Analyze the population demographics and needs.
- Connect with patrons with disabilities, your city, and disability related-organizations.
- Evaluate your library spaces. Take into account lighting, sound, use of color, décor, learning styles, and age.
- Implement diverse programs like Sensory Storytimes, Next Chapter Book Clubs, life skills programs, and parent workshops. (Grassi, 2017).

Taking the time to thoughtfully consider what may need to go into such a comprehensive strategy is necessary for the success and implementation of any program, especially one tailored to the needs of autistic people. Being able to connect and make the best use of a library space for an autistic individual is vital. Having the most accurate and up-to-date information can be the difference between helping many or a few people. Strategizing the best ways to help an autistic person can be challenging but worthwhile as well.

Perspectives of Librarians with ASD

Charles Remy: The Perspective of a Librarian with ASD

Some librarians, especially those with ASD, face the same challenges as patrons. How are they meeting these same challenges and how do they feel about the efforts being enacted to serve them and others with autism? Looking at it from a different angle, what might a librarian with ASD say about what is being done to put focus on this issue? In an interview done by Alice Eng with Charlie Remy, the Electronic Resources and Serials Librarian at the University of Tennessee at Chattanooga, one can begin to see through the eyes of an individual with ASD. He mentions his reasons for entering the library scene, and the advice he would give to library management on autism:

I decided to become a librarian for 3 primary reasons: early childhood exposure to public libraries, an extremely positive undergraduate library experience, and my love for information in all formats... organizations such as the ALA should have diversity initiatives

that include neurodiversity. Many large research libraries have diversity residency programs for new graduates... I'd love to see a few neurodiverse residency programs at academic libraries... [To managers:] ... have an open mind and don't define the person by their autism. Autism is an important part of our identity but it's only a part. Some of the qualities I look for in a good boss are providing clear and detailed instructions, flexible, and willing to make accommodations when necessary, and a clear and direct communicator..." (Eng, 2017, paras. 5-39).

It is interesting to see firsthand the thoughts and views of someone with ASD working in the library field and making his input and diagnosis known. It lends credence to anyone with special needs wanting to pursue a career in this field and their ability, through sheer hard work and determination, to make a path for themselves just like others. Those with ASD ask for the same respect as the rest of us. More opportunities should be opened for this section of the population, to find ways to accommodate their needs and find solutions to their challenges.

Philip Zupon: His Story

Stories of autistic librarians like Charlie Remy illustrate the growing awareness for frontline librarians with autism. According to Dr. Amelia Anderson, Assistant Professor at Old Dominion University in her article "Employment and Neurodiverse Librarians," those with autism still face barriers and setbacks to gain entry or continue in their success within the library profession (2018). Librarian Philip Zupon, also diagnosed with ASD, felt upon graduating with his MLIS that he missed "some social cues unique to the profession... that held the keys or secret code needed to open the right doors" (Anderson, 2018, p. 2). It is easy for someone with ASD to feel as if they were inept in noticing vital social cues or the ability to interrelate with coworkers. For her part, Dr. Anderson hopes she will be able to work with library self-advocates to gain a clearer understanding into the experiences of librarians with ASD and focus in on how the library profession can become more inclusive of autistic people in the future.

Workplace Challenges for Librarians with ASD

Within the workplace, as illustrated by Charlie Remy, there is a stereotype that autistic people are not relatable or empathetic, and that is not true. The job of a librarian is busy, and at times overwhelming for

librarians with ASD. During their busy work life, there is a fear of disclosing their diagnosis. If they did, could it provide clarity and make a difference in someone's life? Most definitely. According to Justin Spectrum, an autistic children's librarian and a blogger, "I believe that being open about my diagnosis could be beneficial to others, i.e., perhaps a child who has an autism diagnosis will see that they can have a career and excel at something... What I fear is a lack of acceptance" (2017, para. 7). Being transparent about one's diagnosis can be scary and beneficial. When one looks past an autistic librarian's social awkwardness and focuses on their skills and sees what they can contribute to the whole organization, there leaves room to connect, relate, and see a unique individual. As the stories and experiences of Charles Remy, Philip Zupon, and Justin Spectrum have illustrated, there are a lot of unintentional barriers, misconceptions, and misunderstandings of autism which can serve as lessons to clear the way for more understanding and inclusivity within the library workplace.

Future Career Opportunities in Libraries for Autistic Librarians

Perspectives of Library Management

Future career opportunities for autistic librarians are guaranteed under the Americans with Disabilities Act. According to Zia Sherrell, a digital health journalist for Helpadvisor.com, "The Americans with Disabilities Act protects people with autism and allows them equal access to employment, government services, and more" (2021, para. 1). Though accessibility is guaranteed, and inclusivity is the goal in libraries, it is not always immediately seen in the promotion and employment process of a library employer of autistic individuals. In Canada this is clear. According to Lori Giles-Smith and Emma Popowich in the scholarly journal *Critical Librarianship*, "personal preference and nominations from members of the 'in group'" play a key role in the "... promotion processes in academic libraries and evaluations of the social performance of the individual" (2020, p. 113). To say that skill and experience does not count would be short-sighted. The social abilities of an individual are worth more in the eyes of management than their skills and experience. This philosophy is unfair to people with ASD who do not excel in a socially-based system. This is slowly changing among employers, even in libraries.

It is interesting, then, to see what library management may say about autistic individuals when asked a fixed set of questions when going through the interview process. For our purposes, these questions may include whether they would hire a person with autism, whether they would be fully transparent and be willing

to disclose their disorder or not and be willing to go through a trial period as a potential reference librarian candidate. Tracey Thompson, Assistant Manager of Library Operations for the Midwest City Library, had this to say:

I would not automatically exclude someone with a disability... one, it is illegal to do so, and two, I could be missing out on some good talent. ... Personality is not my first consideration. Skills rank much higher. I would not want someone to disclose that they have a disability... it would open up legal issues. (HiringLibrarians.com, 2012)

Lauren Philips, Associate Dean for Technical Services at J. Edgar, and Louis S. Monroe Library at Loyola University in New Orleans had this to say in response to the questions posed:

“We do have a librarian with a physical disability. We were initially a little concerned about accessibility issues, but she gets around so fast that she leaves me in the dust... My feeling is that, if you can show in a two-day on-campus interview situation that you are comfortable with meeting and talking with people at all levels... we would hire you regardless of the disability” (Weak, 2012, table 8).

What it comes down to from both interviewees' statements is that even if an applicant has a disability, they will not be turned away. If the applicant has the talent and the ability to fill the roles they are asking for in the job's requirements, then they can more than likely be hired, but if they feel uncomfortable performing those roles, it is better to look for something else. It may take a little bit more work on the part of all parties concerned, but as shown here, autistic individuals have the same capabilities and skills to perform the roles of any position. Asking for accommodation and assistance is not a hinderance; it is a part of what someone with ASD needs to be able to be a fully functioning and successful librarian.

Conclusion

As we have seen, there are multiple perspectives coming out of both public and academic libraries showing ways to reach children and adults with ASD. However, as we have learned from Charlie Remy, Philip Zupon, Justin Spectrum and many more, there is still so much more to be done within the library profession, across the U.S. and the world. Definitions of what ASD is will continue to change as will the solutions being found to the challenges for people with ASD. Continued education, encouraging support systems, having

training programs for library staff and the public, creating partnerships, and having forums between libraries nationwide are key steps for libraries to take as they make strides towards serving this branch of the population. What will each one of us choose to do to serve those with an ASD-related learning disability in the future?

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