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Abstract

Autism prevalence is growing, and autistic people themselves are important in the library and information science field, both as library patrons and employees. Including them in all stages of research about the neurodivergent experience is valuable, and their input and participation is increasingly used in technology research, particularly usability studies. Neurodivergent persons also have unique abilities that align with a wide array of information professions and accommodations can be made that allow them to thrive in the workplace. It is critical that meaningful involvement of autistic individuals is a component of making policy at all levels.

Introduction

The population of individuals diagnosed with autism spectrum disorder (ASD) has grown, but current literature regarding autistic adults lacks first-person accounts, particularly in the information environment. Adult voices have been drowned out by the overwhelming emphasis, both in the general public and the scholarly literature, on early identification and intervention for young children with autism (Cox et al. 2017). Much research on college students with ASD also focuses on the perspective of the professor or instructor, not the students themselves (Barnhill 2014). Achieving a representative sample is vital to the validity of social research findings, particularly when findings are used as evidence to inform social policies and programs.

Likewise, autistic individuals often seek employment in information settings such as libraries and computer technology. This paper discusses the involvement of persons with ASD in library and information research and employment more broadly, and also specifically within the context of several recent studies.

Review of Literature

Autism as Neurodiversity

The current prevalence of ASD in the United States is 1 in 59 persons; this prevalence does not change as children grow to adults, as autism is lifelong disorder (Center for Disease Control 2018). Persons diagnosed with autism exist on a spectrum, with or without the presence of additional intellectual disability (Jaarsma and Welin 2012). Although some with autism were previously classified as having Asperger's syndrome, the growing neurodiversity movement among self-advocates with ASD view autism as a natural variation in neurological functioning no more significant than "differences in skin color or sex" (Jaarsma and Welin 2012, 23).

The Autistic Self Advocacy Network (2018) within the broader context of the disability rights movement, seeks to bring about more accommodation and acceptance of neurological diversity in society. Their slogan, "Nothing About Us Without Us" emphasizes their goal to have meaningful involvement of autistic individuals in making policy at all levels which includes research studies.

Neurodiversity in Library and Information Research

Participant Recruitment

Recruiting autistic adults into research poses particular difficulties (Haas et al. 2016). They can be considered a hard-to-reach population described as, "one in which the "populations are difficult for researchers to access" (Sydor 2013, 33). Several unique factors make persons with ASD a hard-to-reach population for research recruitment and participation. Some wish not to disclose their diagnosis, preferring not to "other" themselves. As such, these individuals would be unlikely to want to participate in a study which relies on their disclosure.

In recruiting adults with ASD without intellectual disability, one study discerned that effective methods include "social media of autism support networks, support groups and service providers; assistance from active, high-profile and well-connected advocates in the high functioning autism spectrum community, and snowballing - by encouraging neuro-typical participants already recruited to the study to enlist relatives and friends with ASD to also join" (Sadler et al. 2010, 370).

Additionally, participants want to be heard and understood as equal and valued partners in research in order to both improve community understanding of ASD and to participate in the wider community. Furthermore, some individuals wanted to be key decision makers in research, based on concerns that their views are commonly misrepresented, misinterpreted and misused by the wider community, especially neurotypical researchers (Sydor 2013).

Research about Neurodiverse Persons

The number of formal studies that have been conducted on the subject of autistic persons and their information needs and abilities are infinitesimal. Anderson investigated how autistic students describe their experiences in the academic library, as well as barriers they face, while utilizing the library and its resources (2016). It was determined that students use their academic library similarly to their neurotypical peers – while also using the library as an escape from overwhelming sensory environments on other parts of campus (Anderson 2016; Ard et al. 2006). The concept of the academic library as sensory escape was recently corroborated in a portion of a study by Sarrett (2017).

A recent study utilized wayfinding, Think Aloud Protocol, Retrospective Think Aloud Protocol, and a wearable camera, to examine the actions, thoughts and feelings of an autistic student and a neurotypical peer as they navigated their campus library in search of materials. The library website, virtual maps to resource locations, and library workers, served equally as enablers and barriers to both students in their information seeking. It was also demonstrated in this study that participant viewpoint ethnography is a viable research methodology for both neurotypical college students and those with autism (Everhart and Escobar 2018).

Research with Neurodiverse Persons

In another domain of information science, autistic individuals have served in the participatory design of technology by being potential users of the technology (Benton and Johnson 2015). One example is in the design of a virtual reality platform geared towards addressing the communication needs of some ASD populations (Politis et al. 2017). By gaining their insights into the appearance and usability of the virtual world and the appropriateness and usefulness of the training materials, the final product has been deemed more useful. The

collaboration of autism research and affective computing at the MIT Media Lab to develop new tools to assist persons with autism operate in the world around them has been shown to provide an overall better socioemotional experience to all people who use it (Madsen et al. 2009).

In the aforementioned information seeking study, researchers consulted with two autistic academic librarians in constructing wayfinding tasks for users on the autism spectrum (Everhart and Escobar, 2018; Mazurek et al. 2012). Benton and Johnson (2015) maintain that user involvement of any form offers people with ASD the chance to have a voice.

Employment in Information Settings

Employment rates for autistic adults are shockingly low. One study determined that only 58 percent of young adults on the autism spectrum worked after completing high school. This is lower than nearly every other population with disabilities studied, including those with an intellectual disability (Shattuck et al. 2012). However, this population has strengths and interests that align with information professions such as logical reasoning, willingness to perform repetitive tasks, and the ability to find different unique solutions to problems (Lorenz, Reznik, and Heinitz 2017).

Employment in Technology Fields

Many autistic people have an interest in and affinity for technology (Mazurek et al. 2012). Famed autism self-advocate Temple Grandin specifically suggests that parents of autistic children consider preparing them for careers in computer programming (Grandin 1999). Popular culture suggests that many members of the technology industry already may be "closeted or undiagnosed autistics" ("Diagnosing Bill Gates" 1994).

The following list provides an overview of technology companies that currently offer supported job environments for persons with autism (Lorenz, Reznik, and Heinitz 2017).

- The German software company, SAP, employs 100 autistic individuals, spread throughout eight countries.
- Auticon, an IT company, employs autistic individuals as consultants and highlights how these employees are often able to work more detailed, concentrated, and systematic than neurotypicals and have different ways of looking at problems.
- Meticulon is a Canadian IT startup company that employs only autistic individuals as IT consultants.
- The Israeli military has become aware of the strengths of autistic individuals. In their Special Intelligence Unit 9900, young autistic adults use their above-average visual perception skills for various geography-related tasks, for example, mapping or analyzing satellite images for the smallest changes.

Employment in Libraries

Information about autistic individuals working in libraries is primarily anecdotal but in one study of library use by persons with autism a body of information emerged concerning going to school to study library science, working in a local library, or even giving one another advice about potential careers in the library (Anderson 2016).

Various librarians describe entering the profession because of a familiarity and level of comfort with libraries, from the public library in childhood to their own college library experiences (Ard et al. 2006; Van House 1988). Unsurprisingly, this phenomenon is also true for autistic librarians - that they are often drawn to the profession from previous positive experiences with

reading, learning, and exploring interests at the library (Anderson 2016). As noted by librarian and autism self-advocate Emily Lawrence, "the notion that all autistics are well suited to certain kinds of repetitive labor but ill-suited to complex, demanding professional practice is false," and many individuals with ASD can also find challenging and rewarding work in positions of responsibility within the library field (Lawrence 2013). Previous studies of autistic employees in libraries relied heavily on repetitive acts such as shelving, though the true employment experience for autistic librarians is much more robust. Though Lawrence suggests that there are many librarians with ASD, she also posits that many of them are reluctant to disclose such information as their diagnoses and, as a result, there is "virtually nothing in the LIS literature discussing autistic librarians or information professionals" (103).

Employment in Academia

The number of persons on the autism spectrum employed as professors is unknown. Much like recruiting participants for research studies, many autistic professors choose not to tell their colleagues fearing they will be perceived as less capable (Diament 2005). In a blog post, "On Being Autistic in Academia," an anonymous writer says "I don't personally know anyone in academia who is openly autistic. Due to this, I find it hard sometimes to make sense of where I belong."

Dr. Hans Asperger referred to his young patients as "little professors" because of their tendency to become very knowledgeable about their special interests and to lecture other *people about those interests. Perhaps the most recognized autistic academic is Dr. Temple* Grandin, a professor of animal science who frequently speaks on autism and animal behavior and who had an HBO film made of her life. It has also been implied that Paul Dirac, Nobel Laureate in Physics and Alan Turing, pioneering computer scientist and breaker of the enigma code, are two renowned figures regarded by some to have been autistic, though never having a diagnosis ("Could a Person with Asperger Syndrome Become a University Professor?", 2018).

Despite concerns, academe is generally considered a more welcoming environment than most for autistic people. "They get paid to talk at length about their area of interest in a realm where eccentricity and limited social skills are often seen as signs of genius rather than cause for scorn. Universities are probably the place where we get the kindest treatment, where we are respected and valued the most," noted one autistic professor (Diament, 2005).

Conclusions

Library and information science research involving autistic individuals has been slow to evolve, but vital. As the neurodiversity movement gains momentum, more understanding will be required as it is important not to speak for a population without gathering their input. Awareness and support in the workplace will also be necessary as this population grows, and the ultimate rewards of inclusion of neurodiverse persons will be beneficial to society (Lorenz, Reznik, and Heinitz 2017).

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