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## **Autistic Users in the Academic Library**

One of the important values for libraries is to provide equitable service to all users. To provide equitable service, it is important to consider the needs of all different categories of users, including those who are disabled. Each disability is different and has varying needs. This paper looks at one disability: autism spectrum disorder, or ASD. According to the CDC, ASD is “a developmental disability that can cause significant social, communication and behavioral challenges” (Centers for Disease Control and Prevention [CDC], 2020). The DSM-V describes two main criteria for a diagnosis of ASD: “persistent deficits in social communication and social interaction across multiple contexts” and “Restricted, repetitive patterns of behavior, interests, or activities” (American Psychiatric Association [APA], 2013). Social deficits may include difficulty with eye contact, or difficulty communicating emotions. Repetitive behaviors may be movements or sounds. Many autistic people also have a “special interest”, which the DSM describes as “Highly restricted, fixated interests that are abnormal in intensity or focus” (APA, 2013). One of the important things to understand is that it is a spectrum disorder, and each autistic person may have any different combination of characteristics with varying degrees of severity. There are a couple things to take note of concerning terminology in this paper and the previous literature. The DSM-V combined an array of conditions that were previously separate diagnoses into ASD, including autistic disorder, pervasive developmental disorder not otherwise specified (abbreviated as PDD-NOS), and Asperger syndrome (CDC, 2020). Since this is a relatively recent change, the literature may refer to any of these terms. Likewise, users may have different diagnoses based on which version of the DSM was in use at the time they were diagnosed. The other consideration is the choice to use identity-first language i.e., autistic person, rather than person-first language i.e., person with autism. Though most of the literature uses person-first language, and there is some debate about this topic among autistic people, this paper follows the Autistic Self-Advocacy Network in using identity-first language (Brown, 2012).

The studies chosen for this paper mostly focus on the experiences of autistic students in higher-level education. The number of autistic children diagnosed is increasing as shown by data from the CDC (CDC 2020). With the increase in rates among children, there is also an increase in autistic students pursuing higher education (Shea and Derry, 2019). Autistic university students are likely to be labeled as “high-functioning”, though this is a controversial term (Anderson, 2018). Labeling an autistic person as “high-functioning” obscures the fact that they may still need supports. Cho lists four challenges for autistic students in higher education: “executive functioning, central coherence, rigid and literal thinking, and sensory confusion” (2018).

## **Theories and Models**

Wilson's model of information needs, which falls under this category, considers how information needs are related to other types of needs. He describes three types of basic human needs: physiological, affective, and cognitive (Wilson 1981). He theorizes that information needs are caused by one of these basic human needs. Another important part of Wilson's model is his focus on barriers (Naumer & Fisher, 2009). Wilson (1981) discusses how "personal, interpersonal, and environmental barriers" can make it more difficult or even prevent a user from fulfilling an information need. This idea can be especially useful when considering disabled users, as they may have more barriers to access.

O'Leary's study uses Wilson's model to explain the autistic user's information needs regarding their special interest (2011). She shows how the information fulfills basic human needs, including social needs as well as personal fulfillment (O'Leary, 2011). While many of the studies mentioned do not explicitly mention a model of information need, barriers are frequently discussed. An example of an environmental barrier for autistic students is if the library is too loud (Anderson, 2018). If an autistic student has a sensitivity to sound, a noisy library may make it harder for that student to navigate and to process information. Personal barriers may include a lack of knowledge about resources available in the library. An interpersonal barrier mentioned in the studies is autistic students' anxiety around interacting with unfamiliar people (Pionke et al. 2019; Cho, 2018).

### **Methods and Techniques**

A variety of techniques were used in the referenced studies. Anderson (2018) used a qualitative content analysis of the website wrongplanet.com. She used the search "library; librarian; lib; AND college; university; uni; campus" to find message threads, which were then read to determine if they were relevant. While this sort of content analysis can be done quantitatively, Anderson chose to do a qualitative analysis to "understand experiences as described by the individuals themselves" (2018, pp. 648). Research on autistic individuals often focuses on the viewpoints and impressions of those around them, such as parents or teachers. By using the qualitative analysis and the autistic students own words, Anderson positions her research in a unique place in the literature.

James Cho uses a case study of the Bridges to Adelphi program at Adelphi University to look at how academic libraries can assist autistic students. This program is offered to support students through their education at the university. The support the library provides these students is a small part of the program. Cho describes different strategies the librarians associated with the program use and whether these strategies have been successful or not (Cho, 2018).

Pionke, Knight-Davis, and Brantley studied a similar program at Eastern Illinois University call the Students with Autism Transitional Education Program, or STEP (2019). Like the Bridges to Adelphi program, the library at EIU partners with the STEP organization, but is only part of the program. The researchers used a structured interview to study "perceptions and use of libraries" by the participants (Pionke et al. 2019). The interviews were analyzed and the authors determined three major themes: "using the library, interaction with library employees, and recommendations for change" (Pionke et al. 2019).

O'Leary studied the information behavior of a single autistic user (2011). She used a combination of interviews and observation. She interviewed both the user and his father, but observations were only of the autistic user. Though this study had a limited scope, it offers intriguing information about an autistic person's information needs regarding their special interest, and merits further study.

Yechiam and Yom-Tov (2021) used data from the search engine Bing to look at the search behaviors of autistic users to the search behaviors of non-autistic users. The researchers looked at all the data for English-language searches from the month of November 2019. They identified a group of “self-stated” autistic users by including any user with a search query such as “I have autism” or “I’m autistic” (Yechiam & Yom-Tov, 2021). The researchers looked at how users scrolled for each search query, how many times they scrolled, response times, and number of clicked links. They looked at data for general text searches as well as for image searches.

Gillespie-Lynch et al. (2014) used an online survey to study the perceived benefits and functions of computer-mediated communication for autistic users. The survey was advertised on ASD and disability themed forums, Facebook groups, and Myspace groups. They used a comparison group of users who did not identify themselves as autistic. The survey included demographic questions, the Autism Spectrum Quotient, which is a questionnaire that assesses a person’s ASD characteristics, and a “survey of internet preferences and socialization” (Gillespie-Lynch et al., 2014).

### **Information Needs and Behaviors**

Some of the information needs for autistic students are the same as those for neurotypical students, such as needing materials for class assignments. However, studies point to a few information needs particular to autistic users. The first is information related to their special interests. Autistic users will use library materials to pursue information about their special interests (Anderson, 2018). Special interests can be very important to autistic individuals. In O’Leary’s study of an autistic young adult, she found his special interest to be an important part of his identity, as well as a way for him to socialize (2011).

Another information need for autistic students is for information about the library and resources available to them. One of the challenges mentioned for autistic students is “sensory confusion” (Cho, 2018). Both the studies by Anderson (2018) and by Pionke et al. (2019) discuss sensory needs of autistic students. Some users described the library as being too loud, while others described it as being too quiet (Anderson, 2018). Users also described the importance of privacy or limited distraction (Anderson, 2018; Pionke et al., 2019). This becomes an information need because the users need the information about where in the library to study. They need to know which parts of the library are for quiet individual study and which parts are for loud group work. They need to know where private study rooms are and how to access them.

The final category of information need for autistic students is not actually about their own acquisition of information, but about that of the librarians they may work with. Anderson states “the more a campus community is knowledgeable about ASD, the more likely they are in helping students with ASD succeed” (2018, pp. 655). Cho also talks about the importance of education about ASD for working with autistic users. (2018). Understanding autistic users’ communication methods and unique needs is essential for being able to support them.

One of the main findings of the reviewed research is that autistic users often prefer to communicate through computer-based methods. Gillespie-Lynch et al. studied how autistic people use “computer-mediated communication” and the benefits they perceive from this use (2014). This study focuses on communication rather than information, but information is shared through communication, so it is relevant to the information behavior of autistic users. Communicating through the internet helped autistic adults feel like they were better able to

understand and to communicate themselves, through having more time to process as well as giving them practice with interactions (Gillespie-Lynch et al., 2014). Non-autistic adults surveyed were more likely to report that the internet did not help them to communicate (Gillespie-Lynch, et al., 2014). This is reflected in the study by Cho which details how a webinar was more effective for teaching information literacy to autistic students than an in-person class (2018). The webinar reached more students, and the students showed more retention of the concepts (Cho, 2018). The use of the Wrong Planet forums also shows how autistic students communicate online (Anderson, 2018).

Autistic people have been shown to be more thorough in general internet searches than non-autistic users (Yechiam & Yom-Tov, 2021). They scroll further down the page and thus look at more results of a search and click on more results as well (Yechiam & Yom-Tov, 2021). This result was not found for image searches, which Yechiam and Yom-Tov theorize may be related to the higher visual load compared to text searches, which can be more difficult for autistic users to process (2021). This study looked at a wide range of autistic users, not just university students, but the findings should still be applicable in the more specific case. This points to the possibility that autistic students may be more thorough when searching for information, however, they still may need instruction in evaluating information (Cho, 2018).

### **Information Sources and Services**

Autistic students are more likely to seek information from people they are already familiar with (Cho, 2018; Pionke et al., 2019; Shea, 2019). Social anxiety related to communication difficulties makes autistic students more comfortable seeking help from people they know (Cho, 2018). This is evident in students in the STEP program, who were most likely to ask their STEP advisors for assistance rather than asking librarians (Pionke et al., 2019).

One of the main themes Anderson described was the use of the library as a space (2018). Many autistic students described the library as an escape (Anderson, 2018). They also described it as a good place to study (Anderson, 2018). As previously mentioned, sensory problems can make autistic students very particular about their study environment (Anderson, 2018). They may want to use private study rooms or study carrels (Anderson, 2018). These are important resources to have available for autistic students.

### **Related Issues and Considerations**

An important consideration for this user group is how to teach information literacy. Cho discusses experiences teaching information literacy to autistic students in the Bridges to Adelphi program (2018). They first offered an in-person seminar which had low attendance, but when they created an online webinar using principles of universal design, the attendance was much greater, and they received positive feedback from students (Cho, 2018). This shows that having online learning options can be helpful for autistic students. O'Leary discusses information literacy in the context of special interests in her study of an autistic teenager (2011). This teenager's information skills were "highly developed in relation to his special interest" (O'Leary 2011). This points to the idea that using autistic student's special interests could be a good way to teach them information literacy.

Another important consideration for this user group is accessibility. While autistic students in K-12 education are covered by IDEA and are given IEPs to be successful in their education, once in higher education, ADA is what is applicable (Shea & Derry, 2019). The ADA describes the legal requirements for accessibility (Shea & Derry, 2019). Familiarity with ADA requirements is a good start to attain accessibility, but it is important to go further, and to consider the individual needs of people with different disabilities. It is also important to understand how accommodations are provided by the university. Most universities have an office for accessibility and a process through which students can request and receive accommodations for their classes. Contact with this department is likely to help serve autistic students better.

### **Major Takeaways**

There are a few practical applications that appear in multiple studies. One is the importance of signage. It is helpful to have clear signage detailing whether areas of the library are quiet or not (Anderson, 2018). Pionke et al. note that the EIU library formed a committee to address signage due to needs identified through their study (2019). Clear signage can help autistic students to navigate the library. It also important information on the website is easy to find as well, such as how to reserve a study room. This will not only help autistic students, but other users as well. Another application is the idea of having a personal librarian for autistic students (Cho, 2018; Pionke et al. 2019). For universities with programs like Bridges to Adelphi or STEP, this could be the librarian that works closest with the program. For schools without a similar program, a librarian could work with the accessibility office to reach autistic students who are registered with that office. Having a person in the library they are comfortable approaching for assistance helps autistic students to get help with library resources when they need it. Finally, these studies point towards the need for librarians to learn about ASD. It may be useful for an academic library to provide programming for their librarians to this effect.

Another the implications of these studies is the importance of having online communication options for the academic library. Autistic students may prefer to communicate through email rather than having an in-person reference meeting. It is important to understand the student's needs and not to push for an in-person meeting if they would be more comfortable communicating through the internet. It also shows that online information literacy education is a good option to have as well. Autistic user's thoroughness in searching may be a strength when it comes to information literacy, but they still may need instruction in determining which sources are best. Another important implication of these studies is just how much there is still more to research. There is so much more to understand about the information behavior of autistic students.

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