

Loud Hands in the Library

Neurodiversity in LIS

Theory & Practice

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Introduction

The entrance to the library spilled into reference and circulation desks, self checkout machines, a whirl of human activity. As I stood there, attempting (and failing) to get my bearings, disparate, chattering flocks of undergraduate students floated around me in random formations. I clutched the neat list I had compiled of books and call numbers like a talisman and inside felt the first few flutters of panic.

Constant motion was my only defense against the milieu of the library. It can be difficult to know where my limbs are in space or to anticipate how others will move, but walking quickly in whatever direction still mutes the fear of human interaction and the anxiety generated by spatial disorientation. It is also a more socially acceptable – though less effective – coping mechanism than hand flapping or spontaneous vocalization.

After a few haphazard turns and loops around the first floor, I found an elevator to the stacks, where yellow fluorescent lighting buzzed overhead, vibrating through my eyes and into my brain. Dizzy and nauseous, I marched around several floors of the library with a kind of mock purpose, until I had

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obtained half of the books on my now crumpled list and could leave the library without feeling as if I had failed some sort of strange test.

In truth, I am accustomed to spaces that were clearly designed without someone like me in mind. My sensory integration difficulties, my spatial confusion, my social anxiety: all are constitutive of neurological atypicality that puts me at a systematic disadvantage in a society structured around a rather specific human ideal. Yet while I generally anticipate that most of the places I go will be less than accommodating, this is not the case for libraries. Throughout my life and into the early stages of my library career, I have come to expect more of these institutions. My expectations are tied up with a concept of the library as “safe space,” as well as with the core principals of the field¹. So when the library fails to live up to such expectations – grounded as they are in our stated commitments as librarians – it is important to ask what has gone wrong and how we might go about fixing it.

In this paper, I will show that neurodiversity², or the idea that neurological variations such as my own ought to be understood as normal human differences, represents a knowledge gap in the library and information science (LIS) field. I contend that librarians have a special obligation to generate theory, policy, and practice that is consistent with neurodiversity, and I will explore some of the ways we might do this. The obligation to meaningfully engage with neurodiversity has important implications for inclusivity in libraries, as well as for the ways in which LIS scholars and practitioners write, think, and work.

I. How might we approach neurological difference?

There are a number of different ways to approach neurological difference. Most, however, fall within the parameters of three primary approaches which I will outline here. The first two – medical and social – can be more broadly characterized as disability models, while the third – neurodiversity – is specific to neurological variations.

a. The Medical Approach

The medical model of disability and, by extension, of neurological variation, works to pathologize a particular subset of human differences along a variety of dimensions (e.g., mobility, sensory perception, etc). It is through this medicalizing process that certain differences become disorders, syndromes, and deficits. Significantly, the medical model is the position that most people default to in the absence of considerations against it.

The medical model centers the problem of disability in individuals (Jaeger, 2012) and focuses predominantly on fixing the “deficient” and the “afflicted.” That is to say, it is deeply interventionist in nature, stressing the importance of preventative measures, treatments, and cures rather than accommodation and

societal change. Disabled people are seen as mere “objects of study...to be acted on, shaped, and turned out as best as can be done to fit into the existing social structure” (Linton, 2005). Those who adopt this model usually emphasize the role of health care professionals and the burdens felt by family and caretakers, but focus less on the actual desires of disabled persons.

The medical approach is pervasive in discussions of autism³, which is often referred to as “Autism Spectrum Disorder” and treated as a tragic medical condition or even “epidemic” that primarily affects children (and, consequently, their neurotypical families). Those who take this approach also, more often than not, talk about autism in terms of a linear spectrum from high to low functioning.

b. The Social Approach

The social model is the most common approach to disability among disability rights activists and disability studies scholars. In contrast with the medical model of disability, the social model depicts disability as a socially constructed phenomenon, the product of systematic discrimination. Adherents of this model “[separate] out ‘impairment’ (that is, the functional limitations of our bodies and minds) from ‘disability’ (that is, the disabling barriers of unequal access and negative attitudes” (Morris, 2001)⁴. Of course, this distinction is not without its own complications – after all, the question of what qualifies as an “impairment” still looms large. However, rigorously distinguishing between impairment and disability provides activists with a means to talk about disability as the result of social oppression – similar in some (though certainly not all) respects to race or gender – rather than as a phenomenon centered in “defective” individuals.

c. The Neurodiversity-Based Approach

As a concept, neurodiversity “primarily originated in the thinking of...utistic communities founded during the final decades of the twentieth century” (Baker, 2011).

There is a sense in which neurodiversity – or the concept that neurological differences constitute benign human variation – is an outgrowth of the social model of disability. It depends upon the same fundamental claim that many of the harms of disability do not in fact result from the root impairment(s) at all, but rather from hegemonic social and political structures that disadvantage anyone with a particular sort of atypical trait or traits.

Neurodiversity, however, also draws on the concept of biodiversity, wherein naturally-occurring differences lead to species richness. Many atypical neurological variations, then, are a function of human diversity, and “are properly regarded as non-maladaptive cognitive variations in *Homo sapiens*” (Fenton & Krahn, 2007).

Ultimately, neurodiversity advocates seek “better social support mechanisms, greater understanding from those around them or those who treat them, and a recognition that, though they are neurologically, cognitively and behaviorally different, they do not necessarily suffer from being neurodiverse nor do they need to be cured” (Fenton & Krahn, 2007).

II. How have librarians talked about neurological difference?

Although the neurodiversity movement has gained momentum over the last few decades, there is still a dearth of scholarly work in LIS that touches on its implications for information services. Keyword searches for “neurodiversity”

Content Category	# of Articles	Example Citation
Consumer Health Information	14	Coates, H. (2009). Autism Spectrum Disorders: Wading through the controversies on the web. <i>Medical Reference Quarterly</i> , 28(3), 259-267.
Services for Parents & Autistic Children	11	Halvorson, H. (2006). Asperger’s Syndrome: How the public library can address these special needs. <i>Children & Libraries</i> , 4(3), 19-27.
Designing & Accessing Autism Resources	5	Francis, P, Balbo, S., & Firth, L. (2009). Towards co-design with users who have autism spectrum disorders. <i>Universal Access in the Information Society</i> , 8(3), 123-135.
Assistive Technology	3	Price, A. (2011). Making a difference with smart tablets. <i>Teacher Librarian</i> , 39(1), 31-34.
Representations of Autism	2	Jones, S.C. & Harwood, V. (2009). Representations of autism in Australian print media. <i>Disability & Society</i> , 24(1), 5-18.
Autistic Adults	1	Strub, M.R. & Stewart, L. (2010). Case study: Shelving and the autistic employee. <i>Journal of Access Services</i> , 7(4), 262-268.

Figure 1. Overview of 36 articles from LISTA

and “neurological AND (difference OR variation)” in Library, Information Science & Technology Abstracts (LISTA) return no articles related to

neurodiversity. Inquiries sent to disability studies librarians reaffirmed that, while there is good work that focuses more generally on disability in library contexts, there are not articles dealing specifically with the concept of neurodiversity⁵. That said, there are some articles focusing on autism and libraries, though perhaps fewer than one might expect. As of December 2012, a search for “autism OR asperger* AND library” returned 36 research articles from peer-reviewed scholarly journals. These have been broken down by broad subject category in Figure 1. Notably, all of the articles refer to autism as a disorder and/or syndrome.

An investigation of these articles revealed certain tropes that are indicative of a medicalized approach to autism (though the degree to which researchers emphasize pathology varies). Here, I will point to some of the pervasive problems that demonstrate that the bulk of the literature currently makes use of the medicalized approach to neurological difference⁶.

a. Medical Language

There is no shortage of clinical language in the LIS literature. For example, in a 2007 article in *Health Information and Libraries*, the author notes that “there is emerging evidence that [Asperger’s Syndrome] occurs because the left and right hemispheres of the brain do not communicate correctly” and goes on to assert that “although there is not a cure or specific treatments for AS, many individuals can live productive and ‘normal’ lives” (Lorence, 2007). Akin & MacKinney write that “more than one million people in America suffer from one of the Autistic disorders, and the problem is five times as common as Downs syndrome and three times as common as juvenile diabetes” (Akin & MacKinney, 2004). Other authors also make use of this “suffering from” locution in discussions of autism. Language that centers on suffering, compares autism to diseases like diabetes, focuses on the mechanics of causal theories, or laments the lack of a known cure is pathologizing.

b. Person-First Terminology

Person-first terminology (i.e., “a person with such-and-such-disability”) is the language that is most often used in North America to discuss disability; it “literally means that the person receives greater emphasis than the impairment” (Jaeger, 2012). As a result, in most cases LIS scholars make use of person-first terminology in scholarly articles that focus on autism. However, many members of the Autistic community have a strong, considered preference for identity-first language (i.e., “Autistic,” “Autist,” or “Autistic person” rather than “person with autism”) because we “understand autism as an inherent part of an individual’s identity – the same way one refers to ‘Muslims,’ ‘African-Americans,’ ‘Lesbian/Gay/Bisexual/Transgender/Queer,’ ‘Chinese,’ ‘gifted,’ ‘athletic,’ or ‘Jewish’” (Brown, 2011).

Autism specialists, healthcare practitioners, and parents, more often than not, still use person-first language because they take autism to be a disorder that is separable from the individual. That is, “[person] with autism” suggests that there is a normal person trapped behind the autism” (Jaarsma & Welin, 2012); the idea that an autism cure would essentially reveal the afflicted person’s “true self,” releasing the normal child from the prison of their autism, is a fundamental element of the pro-cure narrative⁷. LIS scholars and practitioners are surely - at least in the vast majority of cases – unaware that this language-based controversy exists, and thus mistakenly default to the conventional terminology.

c. Focus on Children, Parents, & Caregivers

Very few LIS articles mention (and fewer still discuss) Autistic adults. This emphasis on children, families, and their doctors is characteristic of much of the writing on autism outside of the LIS field as well. This is in part because diagnosis and methods of early intervention are significant topics of discussion among those who view autism as a disorder. This systematic focus on children renders Autistic adults invisible.

Parents and caregivers are frequently invoked in these articles, sometimes as intermediaries for their children, other times as panicked information seekers. For example, the author of one article asserts that “receiving a diagnosis of autism spectrum disorder can be frightening and overwhelming for a parent or caregiver” and that “finding a reliable source of information is a great relief” (McCollum, 2012); this statement bypasses Autistic individuals entirely, insofar as it fails to reference the emotional response or information needs that the Autistic person might have in response to a fresh diagnosis⁸. Although the article does go on to discuss a website that provides information for Autistics, it is clear that parents and caregivers are seen as the primary seekers of information on autism, to the exclusion of actual Autistics.

d. The Neurotypical Librarian

There is virtually nothing in the LIS literature discussing Autistic librarians or information professionals. There is one case study that centers on Autistic employees who are responsible for shelving books (Strub & Stewart, 2010), but – in the absence of materials on Autistic professionals – it may do more harm than good.

The librarian is most often treated as the non-Autistic facilitator of information access, with the authors of most articles attempting to explain Autistic traits to a presumably neurotypical audience. This is a problematic depiction, both because it is inaccurate and because it perpetuates the exclusion of Autistic people from the workforce generally and librarianship specifically.

Taken together, these tropes (1) promote inhumane normative evaluations of library patrons, (2) reinforce the systematized pathologization of

neuroatypicality with little regard for evidence or the subjective experiences of Autistics, and (3) inhibit librarians' development of creative and inclusive services that promulgate intellectual virtue and improved quality of life.

Librarians tend to problematically think about Autistics in terms of their symptomology (e.g., “we know that Autistics like repetition because we know that “liking repetition” is characteristic of autism”). Even though authors of LIS articles sometimes note that no two Autistics are precisely alike, they nevertheless tend to slip into a sort of autism determinism. This ultimately results in a library environment wherein the reported desires or wants of Autistics are rarely, if ever, considered, because it is misguidedly believed that everything one needs to know about Autistics can be inferred from their medical classification.

III. How might we do better?

Given librarians' commitments – namely, our dedication to providing inclusive, equitable information services – we are obliged to meaningfully engage with neurodiversity. What follows is a discussion of some of the ways in which librarians might go about doing this and thus improving on the current state of affairs⁹.

a. Change the Autism Discussion

Librarians must produce scholarship that is sensitive to who Autistics are as people, and not as exemplars of the DSM diagnostic criteria. They must disavow ableism and the medical model of disability, both because these are harmful and because they are intellectually irresponsible. Although a reference librarian may not be able to fully fulfill their professional obligations while systematically denigrating materials that take a harmful approach to autism, librarians are not bound by the same ideal of neutrality in their writing, policy, or actions outside of the library itself, and can thus take a more openly activist stance with respect to neurodiversity. A reference librarian can also make an effort to direct users to neurodiversity-friendly materials, which should be incorporated into the collections.

b. Collaborate with Autistics and Autistic-run Organizations

For any LIS theorist or practitioner, endorsing neurodiversity means taking Autistics seriously as a user group and as a community. To do this well, librarians must provide services and programs to Autistics on the basis of evidence that extends well beyond what medical professionals think they understand about autism. This would involve meaningful collaborations with Autistics and with Autistic-run organizations that promote self-advocacy, such as the Autistic Self Advocacy Network. There is a tendency among neurotypical individuals to want to talk to “autism experts” or to an Autistic's caregiver rather than to

the Autistic person. One of the greatest frustrations Autistic self-advocates report is the consistent emphasis on the viewpoint of the “autism specialist,” without any regard for the wealth of knowledge Autistics have about their own lives. Working directly with Autistics ensures that librarians are not relying on health care professionals, caregivers, or anyone else to speak for Autistics in the library. Librarians generally agree that they should work directly with users to determine their information needs. Applying this thinking to Autistics is really just a reasonable extension of current practice. It would also allow librarians to import creative ideas, such as interaction badges that “indicate how much interaction [individuals] are up to” (Sibley, 2012), from the Autistic community into the library environment.

c. Educate Neurotypical Users

A recent study showed that young Autistics whose neurotypical peers received inclusion training “spent less time alone on playgrounds and had more classmates naming them as a friend” compared to Autistics who received one-on-one social skills training (Kasari et al, 2012). In other words, educating neurotypical individuals about Autistic people is an effective means to improving well-being for Autistics. Libraries are well positioned to play an active role in delivering this sort of education to children and adults alike, both in a more formalized group training environment and in appropriate one-off reference interactions.

d. Create Autistic-Friendly Environments

The physical library space can be more or less welcoming depending on the level of attention paid to neurologically diverse users. Older fluorescent lights, for instance, can cause Autistic patrons (and others who are light-sensitive and/or prone to migraines) a great deal of discomfort, and should thus be avoided whenever possible. It is also important to bear in mind that certain shifts in academic libraries towards open “learning commons” environments may be helpful to some users, but can prove intimidating or overwhelming to others. There is no “one size fits all” option, and the move towards privileging collaborative, maximally social learning over individualized, solitary intellectual pursuits can have deleterious consequences not only for some Autistics, but also for those users who are introverted or shy.

e. Develop a Neurodiverse Profession

Librarianship is a notoriously homogenous profession. Although nearly 1 in 5 Americans are disabled, the number of disabled information professionals is still unknown (Jaeger et al, 2011). In the case of autism, the problem of underrepresentation in the field is compounded by overly simplistic thinking, such as when the authors of articles suggest that Autistics are uniquely adapted

to performing monotonous, detail-oriented tasks for hours on end. The notion that all Autistics are well suited to certain kinds of repetitious labor but ill suited to complex, demanding professional practice is false.

One way to combat neurologically-based discrimination and better serve Autistic populations is to hire individuals who are neuroatypical. Active recruitment must, however, be coupled with efforts to make the profession safe for Autistics. As an Autistic librarian who is wary of “behaving autistically” around co-workers, I do not doubt that there are many other Autistic information professionals in our midst who do not feel safe coming out at work. This fear is not unwarranted: the stigma attached to autism is alive and well in the library profession. If librarians are to truly embrace neurodiversity, they must cultivate the requisite knowledge and sensitivities to make the profession safe for a wide variety of persons who present in a range of different ways. This is a crucial first step in making the library a safe space for a similarly wide variety of users.

f. Recognize and Cultivate Alternative Communication

Some Autistics make use of assistive technology and augmentative and alternative communication strategies, devices, and applications (particularly those Autistics who are nonspeaking, but also some who experience temporary language loss). Librarians should be familiar with assistive technology and should make an effort to stay current on developments in the area. However, in addition to their knowledge of assistive technology, it is important that librarians develop an understanding of the myriad ways that Autistics communicate. For instance, various forms of stimming (or self-stimulating behavior) such as hand flapping, rocking, and bouncing are common among Autistics. Stimming can be an indication of excitement, anxiety, frustration, or delight, but it is never meaningless movement. Cultivating knowledge of Autistic body language and communication is crucial to the promotion of neurodiversity and the protection of the patron’s right to communicate.

Conclusion

I anticipate that at least some librarians will find such an endorsement of neurodiversity to be inconsistent with the principles of librarianship as they know them, primarily because they interpret it as a breach of neutrality. Librarians’ are, after all, committed to unbiased service – that is, as the ALA Code of Ethics puts it, we must “distinguish between our personal convictions and professional duties and...not allow our personal beliefs to interfere with fair representation of the aims of our institutions or the provision of access to their information resources.” However, actively engaging with neurodiversity is not a question of favoring particular personal or political beliefs; rather, such engagement is an extension of librarians’ professional duties insofar as

it enables the provision of equitable information services. Furthermore, not engaging with neurodiversity is not a more “neutral” choice simply because it replicates the status quo. Librarians who take it to be so are still inhabiting a substantive political position, one which does actual harms to individuals marginalized for their neurological atypicality. As we make an effort to engage with neurodiversity, libraries and librarianship will become increasingly more inclusive of Autistics and many others. Our profession and our communities will be better for it.

NOTES

1. That is, librarianship is a profession dedicated to making information accessible (where “information access” is a robust concept that entails both physical and intellectual access). Indeed, the American Library Association’s Code of Ethics emphasizes our fundamental role as providers of equitable information services (ALA Code of Ethics, Article I).
2. In talking about neurodiversity, I will focus my attention on the cluster of traits typically classed along the Autism Spectrum. However, my argument should also translate to many other neurological differences (e.g., ADHD, Tourette Syndrome, dyspraxia, etc.).
3. Perhaps the most prominent promoter of the medical approach to autism is Autism Speaks, which is also the most readily recognizable organization devoted to autism. Autism Speaks perpetuates a view of autism as menacing pathology through a variety of means. Notably, its 2009 “I am Autism” fundraising campaign shows a series of video clips of presumably Autistic children – mostly stimming (i.e., engaging in repetitive movements or self-stimulation) or sitting alone – while an ominous voice declares, “I am autism. I’m visible in your children, but if I can help it, I am invisible to you until it’s too late... I work faster than pediatric aids, cancer, and diabetes combined” (ASAN). The language of the “I am Autism” campaign is a somewhat extreme example of the medical approach, but it is broadly characteristic of the way in which many individuals and organizations conceptualize autism: as a dangerous disorder that afflicts children, has catastrophic consequences for neurotypical family members, and demands early medical intervention.
4. While I refer to medical and social models as the most prominent approaches to disability (with medical professionals and the general public most frequently adhering to the former, while disability scholars and activists often adopt the latter), there are other approaches to disability that do not fall cleanly into one camp or the other. For instance, the interactionist approach takes as its main principle the notion that “disabilities arise as a result of the interaction between the social environment and an individual’s range of physical and mental traits” (Barclay, 2011).

5. My interactions with these librarians also served to emphasize that scholars in the education field have written a good deal about neurodiversity. The disparity between these two strongly related fields – LIS and education – is curious and surely apt for further investigation.
6. I should note that references to pathology or flawed language choices are not necessarily an indication that the ideas contained within these articles are irredeemably problematic or misguided. All of the articles I examined were well-intentioned, and many included intriguing ideas for library services directed at Autistics. The problem, then, is largely in how librarians conceptualize autism and, to some extent, disability more generally. This conceptualization has very real implications for how librarians and libraries serve Autistics, but that does not mean that all librarians who consider autism to be a disorder also do bad work, and it certainly does not mean that librarians who adopt the medical model do so maliciously.
7. Prison imagery is common to medicalized autism narratives, which also tend to focus on affected children rather than adults.
8. It is also worth noting that, while many individuals who are diagnosed are in fact children, a growing number of Autistics are diagnosed in adulthood. Some forgo a formal diagnosis entirely for a wide variety of reasons. Among them: the high cost of diagnosis, fear of stigmatization as a result of diagnosis, anti-medicalization beliefs, and so on.
9. This is most certainly not an exhaustive list.

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