"This Is a Quiet Library, Except When It's Not:"

On the Lack of Neurodiversity Awareness in Librarianship

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Abstract

While much has been written about diversity, disability, and specific neurominorities in information studies and music, the subject of neurodiversity as a whole has remained relatively untouched since it first appeared 20 years ago. This paper briefly reviews what few writings do exist, then begins to fill that gap by laying a foundation for future scholarship. The history and vocabulary of neurodiversity are outlined, concepts from Disability Studies are introduced (like identity-first language and models of disability), and neurodivergent voices (besides the author's own) are promoted.

Note: As a neurodivergent person, the author's writing style may not meet traditional (i.e., neurotypical) standards, especially in academia, which can be an especially exclusionary and ableist environment. While he does not wish to be a "bad writer," he also does not believe in altering his authentic, disabled voice simply to make it more palatable for the able-bodied and minded. He would like to thank the editors of this journal for their inclusivity and encourage readers to always seek out and privilege the voices of actual members of marginalized communities.

"You're like a vampire."

It is a few years ago. I am in my mid-20s and in my first full-time teaching job after searching for two years post-graduation. I am a middle school band director in a county with no stoplight and the sixth person to hold this position in four years.

As per usual, I had spent the morning teaching three hours of middle school general music to students who were required to see me while the teachers of their core courses had their planning period. My dream is to become a high school or college director of bands after going to graduate school for conducting, but I only have one band class a day for 45 minutes.

I am eating lunch alone at my desk in my bandroom while NPR softly plays in the background, and the only light sources are a small table lamp on my desk and two windows with their curtains drawn. Middle school students are loud, especially in my room with its tile floor, concrete block walls with no acoustic treatment, and seven-foot drop ceiling, and the nine banks of fluorescent lights are loud to my eyes. When I close my eyelids, I can feel pressure in my head and buzzing in my ears.

I am across the street from the main school building in a smaller structure that I share with the weight room, which is on the other side of my storage room (football is king around here). The physical education teacher/head football coach will sometimes lift then use the bathroom, which is on my side. Today is one of those days.

I do not remember the exact quote because this is not the first time that he has noticed and commented on my accommodations, but I believe that this is the first time that he has compared me to a monster. This makes it stand out and crystallize in my memory. He is only trying to poke fun as a friend might, but we are not friends—not like that.

I look back on that day with a mix of anger and sadness. At the time, I grasped that my working conditions overstimulated my senses (which is why I tried to give them time to cool off), but I only suspected that I might be Autistic. Now that I know for certain and have learned much more about myself and Autism, I am better able to understand what was happening neurologically and why. I am also able to see his remarks for what they are—microaggressions spoken out of ignorance. I confused him, but I was confused too. I did not know why I had always seemed to be different from most other people, which made it difficult to know how to respond when someone would point out a difference. Had I done something wrong? Was something wrong with me? Because of that lack of self-knowledge and awareness, I did not do myself any favors. I did not defend myself or take advantage of teachable moments.

This occurred frequently in the past because I was not formally diagnosed until shortly before my 28th birthday a couple years ago. I sought it out because of the trauma that I endured while at that job (which I still sometimes feel the effects of), and going forward I wanted any possible protections, services, or accommodations that an official diagnosis would unlock. I paid hundreds of dollars out of pocket because I had no health insurance at the time, and it was difficult to find a psychologist willing and able to diagnosis an adult. The burden was on me in every way.

I am writing this because the burden is still on me. I am a former music educator going to graduate school/in debt to become a music librarian. I am a disabled person living in an ableist society. I am an Autistic self-advocate trying to do more than just survive.

Music Librarianship

Like the rest of humanity, neurodivergent people use every kind of library, which is why it is important for every kind of librarian to be familiar with neurodiversity. However, for subject

specialists in the performing arts (especially music), such knowledge maybe be even more essential because of the nature of the subject and its relationship to neurodiversity. As Neil Learner and Joseph Straus point out in their introduction to *Theorizing Disability in Music*:

> Many of these essays demonstrate the advantages of working with a nonverbal medium. Music can represent mental states directly, including those classified as illnesses or disabilities, without the medium of language. That expressive capacity may explain in part the unusual emphasis in this volume on cognitive impairments and mental illness compared to most work on disability.[1]

For example, Autistics are more likely to have absolute or relative pitch than the general population,[2] and several famous musical figures appear to have had at least some characteristics of Autism. A very strong case has been made about Glenn Gould,[3] for instance, although such investigations of the past can be counterproductive. They can contribute to the pop culture myth that savant abilities are a common Autistic trait in those who are not intellectually impaired, and the person being investigated does not have the opportunity to be an active participant in the discussion, either to defend themselves or provide additional evidence.

Instead, it is better to speak with and listen to living Autistics who know that they are Autistic. Well-known self-advocates like Dr. Stephen Shore,[4] John Elder Robison,[5] and Donna Williams[6] have written memoirs that mention the role that music plays in their lives, and Dr. Michael Bakan, professor of ethnomusicology at Florida State University, recently published a book that "re-presents" conversations he had with ten Autistics about "how they make, experience, and find meaning in music and why it matters to them that they do."[7]

Music has been at the center of my life too, and there have been times when being involved in it has been beneficial to me, especially when I was undiagnosed. In her memoir *Pretending to Be Normal*, Liane Holliday Willey writes of a similar feeling:

> I think cultural and performing arts types must be Aspies [slang for Autistics who's form of Autism used to be labeled Asperger's syndrome]. If not, they are surely the next best thing. They are at least amenable friends of Aspies. I found great acceptance among my drama peers, most of whom were extremely tolerant and appreciative of diversities and personal visions. I was able to flourish in such a warm and supportive environment, finding it to be the best place for me to turn many of my AS traits into real and viable assets.[8]

Performing arts libraries can and should be this kind of environment, especially if performing arts librarians actively seek to make them so.

Neurodiversity in LIS Literature

When I saw the call for papers for this special issue on diversity and inclusion, my initial thought was to write about neurodiversity, but when I brought it up to the head of the performing arts library at my university (who I was working for at the time and had disclosed to), he asked me what I was talking about. After I explained, he excitedly expressed his support and curiosity about what had already been written, particularly in music.

That interaction led to this literature review, which is purposely cursory because this article was first drafted for an accelerated summer course in music librarianship. I limited exploration to merely two databases (Library and Information Science Source and RILM), but to get as many hits as possible, I performed a simple search using only the word "neurodiversity." For this editorial, I will focus on only the results from LISS.

Of the thirteen results, ten are book reviews—eight for *Neurotribes: The Legacy of Autism and the Future of Neurodiversity* by Steve Silberman and two for *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and Other Brain Differences* by Thomas Armstrong.[9] Notice how the title of Armstrong's book reflects old models of disability—divine gifts and medical disorders defined by deficits. Neurodivergence is not a gift or a curse, but a state of being. Everyone has strengths and weaknesses, period. Removing someone's impairment would give them a different set of attributes, not make them perfect or their lives hardship-free. However, their life would become easier, in many cases because they would fit into our ableist society better. That does not mean that we should be looking to cure all impairments as a racist society would seek to cure non-whiteness.

The eleventh result is a question and answer section from the *New York Times Magazine* with two reader questions that involve Autism. Neurodiversity is mentioned in the first by a struggling academic in the humanities who self-identifies as a white male who feels that he is "less likely to get a full-time job no matter how well I teach or how much I publish" because of the "movement for greater faculty diversity."[10] A colleague suggested that he "use the idea of neurodiversity to qualify as a diversity hire," but he does not believe that he is Autistic (although he says that a diagnosis might have fit him when he was younger), or that a hiring committee would look favorably on someone who disclosed. He correctly identifies his colleague's idea as a form blackface (performing as a member of a marginalized group to which you do not belong for your own benefit).

One of the issues this problem-riddled question touches on is disclosure, which is a major one (especially in professional settings) for those who have a "hidden" disability. When most people use the word disclosure, what they are really talking about is self-disclosure, which is the

intentional act of disclosing. However, we know that not all communication is intentional or received as intended because we have all experienced miscommunication. One can choose to not self-disclose but still be disclosing something. Some people may recognize indicators of an impairment and respond humanely, while others may miss those signals and respond with prejudice. However, always remember that unless you are a trained, unbiased professional who has consensually and accurately administered diagnostic instruments that you are not qualified to make a formal diagnosis of anyone ever, and that while a formal diagnosis is nice, it is still a medical construct with barriers and stigma attached due to government and society.

People uncomfortable with self-disclosing may believe that by not doing so that they are effectively in stealth mode, flying under the radar of everyone else, when this probably not the case. They may be (understandably) worried about the possible negative consequences of self-disclosure, but not realize that those same possibilities exist regardless of their choice, and that by not fighting stereotypes they are contributing to them. Choosing to be proactive and self-disclose could provide access to accommodations, raise acceptance of their impairment through education and experience, and provide a beacon for other still-closeted/undiagnosed colleagues. Choosing to be reactive and self-disclose only after problems have arisen could be too little, too late.

It is not until the twelfth result that we finally hear from a neurodivergent person (or at least a self-advocate who is comfortable with the fact). In "Neurodiversity in the Library: One Librarian's Experience," Alice Eng correctly points out that "the literature about neurodiversity and libraries is heavily skewed towards libraries accommodating neurodivergent patrons;" "there is little is written about librarians who are neurodivergent and their professional experiences;" and "diversity is a word frequently used in the library profession. The literature that currently

exists typically focuses on gender, ethnic, cultural, and sexual diversities. One group that is rarely mentioned is the neurodivergent."[11] In response to this gap, Eng interviewed Charlie Remy, an Autistic university librarian, and when she asked him why this void exists, he answered:

> I think some of this has to do with the continued societal focus on children with autism, although this is slowly changing. Autistic kids grow up and deserve meaningful employment opportunities. In addition, professional organizations such as the American Library Association should have diversity initiatives that include neurodiversity. Many large research libraries have diversity residency programs for new graduates of library schools. I'd love to see a few neurodiverse residency programs at academic libraries. These could serve as a good professional entry point for those on the spectrum. Finally, more librarians on the spectrum need to feel comfortable enough to disclose so these conversations can happen.[12]

I agree with him wholeheartedly, and he provides a nice segway into Emily Lawrence's "Loud Hands in the Library: Neurodiversity in LIS Theory and Practice," the only result written by a neurodivergent information professional (ironically, while they were at the same university that I am now). It is organized around three questions: 1) what approaches are there to neurological diversity; 2) how have librarians talked about neurological difference; and 3) how might librarians do better? Lawrence's December 2012 search of Library, Information Science, and Technology Abstracts returned zero results for "neurodiversity" and "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 neurodiversity."[13] It appears that little has changed since.

Disclaimer

Autistics reflect not only the variety present in Autism, but the variety in humanity. This fact extends outward to neurodiversity, the disability community, and all marginalized groups. Membership is based around an identity, but members are not homogenous. They can be represented by a single member, such as on a commission or council, but that person is not an exact representation of every member.

I self-advocate at a formal level because I realize my privilege as a white man in the United States, a graduate student, and an Autistic who can speak, live alone, and drive himself. I have a responsibility to use my privilege to help others and not just myself. When I do so, I am practicing self-actualization and empowering myself and others.

What I do not want is to be a "self-narrating zoo exhibit,"[14] the token neurodivergent person in the room, or the one speaker for all neurominorities all the time. I am only one Autistic, and Autism is only one neurominority. My perspective on the lives of others is limited to what I have been able to learn about them (shared in their own words, if possible). I would prefer that you not only listen to me, but to them as well, then come to your own conclusions based on a body of evidence.

Language

When referring to myself, I use what is called identity-first language, rather than person-first language. This means that I call myself an Autistic or Autistic person, rather than a person with Autism. Jim Sinclair, one of the first formal Autistic self-advocates, outlines the reasons why people do this in "Why I Dislike 'Person First' Language."

Saying person with Autism suggests that: 1) "the autism can be separated from the person;" 2) "even if autism is part of the person, it isn't a very important part;" and 3) "autism is something

bad—so bad that it isn't even consistent with being a person."[15] He goes even further in what can best be described as the first Autistic manifesto, "Don't Mourn for Us:"

> Therefore, when parents say,
>
> I wish my child did not have autism,
>
> What they're really saying is,
>
> I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.
>
> Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.[16]

He points out that "characteristics that are recognized as central to a person's identity are appropriately stated as adjectives, and may even be used as nouns to describe people" and that "it is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person."[17]

For example, "musician" is used much more often than "person with musical ability," both by people who do and do not identify as such, and no one has ever tried to change that because society views music as good and disability as bad. Most musicians have been told some variation of "I wish that I could be like you—perform music well enough to consider myself a musician," while no one has ever learned that I am Autistic and then expressed a desire to be Autistic too.

I do not blame them for this, though, as our ableist society does disable people and make their lives more difficult. It is important to make connections between this and other forms of discrimination—society can disable anyone in any way for any reason, not just impairment

(voter suppression efforts that target people based on race/ethnicity, for example). That does not mean that these people should feel ashamed of themselves or their circumstances, or that they need to be separated from the identity that is being used as an excuse to justify discrimination.

I capitalize Autism because of the rising idea of Autism as culture,[18] something which already exists in other disability communities, most notably among the Deaf. There are now more Autistics than ever, not because Autism is an epidemic that continues to spread, but because more Autistics are being recognized or recognizing themselves. This includes Autistics like me with the linguistic, communication, and intellectual abilities that allow us to represent ourselves and create works of "high culture" like memoirs, visual art, and performance art. The Internet has allowed us to more easily find and connect with each other, which has been of huge benefit considering our desire to socialize but our struggles with the act itself, especially in-person and possibly surrounded by people who do not understand or accept us as we are. We have shared with each other information about the Disability Rights and neurodiversity movements, the field of Disability Studies, and the work of other self-advocates. Together, we continue to forge community amongst ourselves and acceptance in the wider world.

History

Judy Singer, with help from Harvey Blume, first coined the word neurodiversity 20 years ago.[19] At the time, she was an undergraduate sociology student at the University of Technology Sydney, writing her thesis "Odd People In: The Birth of Community Amongst People on the Autistic Spectrum: A Personal Exploration of a New Social Movement Based on Neurological Diversity." It became the basis for her chapter in *Disability Discourse*, a volume in the "Disability, Human Rights, and Society" series and published by Open University Press in 1999, in which she wrote:

For me, the key significance of the "Autistic Spectrum" lies in its call for and anticipation of a politics of Neurological Diversity, or "Neurodiversity." The "Neurologically Different" represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability.

The rise of Neurodiversity takes post-modern fragmentation one step further. Just as the post-modern era sees every once too solid belief melt into thin air, even our most taken-for granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) are being dissolved.[20]

The motivation behind her research came from the new idea of Autism as a spectrum of somewhat different but related disorders, which allowed her to recognize Autism in herself, her mother, and her daughter. "Classic" autism did not fit any of them, but Asperger's syndrome did.

Harvey Blume is an American journalist who collaborated with Singer after they met on Martjin Dekker's "Independent Living on the Autistic Spectrum" listserv (InLv). The quicker turnaround time in his profession meant that he was the first to publish about "neurological pluralism" in *The New York Times* in 1997,[21] then about neurodiversity in *The Atlantic* in 1998[22] (in which he does not credit her). This led to confusion about who came up with the word first, but recent histories of Autism,[23] as well as a reprint of her thesis with a forward by her,[24] have settled this issue once and for all.

Vocabulary

In the two decades since, a collection of terms that comprise the basic vocabulary of neurodiversity have been assembled and refined, but this evolutionary process has led to misunderstandings and misuse of these words. In an attempt to remedy this, Autistic self-

advocate Nick Walker provides definitions and examples in a 2014 post on his website *Neurocosmopolitanism.*[25]

Neurodiversity is the "diversity of human brains and minds—the infinite variation in neurocognitive functioning within our species." It is a biological fact, unlike the **neurodiversity paradigm**, which is a philosophical framework built around three principles: 1) "neurodiversity is a natural and valuable form of human diversity;" 2) "the idea that there is one 'normal' or 'healthy' type of brain or mind, or one 'right' style of neurocognitive functioning, is a culturally constructed fiction;" and 3) "the social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity."

The **neurodiversity movement** is a social justice movement based on this paradigm. One of its main positions is the rejection of pathologizing more intrinsic forms of **neurodivergence**, but acceptance of consensual medical treatment to remove more extrinsic forms that are not core to personhood. For example, epileptics would like to be rid of seizures, while many Autistics do not want to be rid of their Autism.

People who have "a style of neurocognitive functioning that falls within the dominant societal standards of 'normal'" are **neurotypical** (NT), while those who have "a brain that functions in ways that diverge significantly" from those standards are **neurodivergent** (ND). This includes people with neurodevelopmental conditions (Autism, attention-deficit/hyperactivity), neurological conditions (epilepsy, Tourette syndrome), learning impairments (dyslexia, hyperlexia, dyscalculia, dysgraphia), and mental health conditions (primarily those that are neurological rather than psychiatric, like obsessive-compulsive, bipolar, chronic anxiety/depression). Neurodivergence can be innate and genetic, caused by a brain-altering

experience (such as traumatic brain injury), or a combination of the two. A person can possess

more than one form of neurodivergence and be **multiply neurodivergent**.

A **neurominority** is a population of neurodivergent people who have the following in

common: 1) "they share a similar form of neurodivergence;" 2) that form is "largely innate and

inseparable from who they are, constituting an intrinsic and pervasive factor in their psyches,

personalities, and fundamental ways of relating to the world;" and 3) that form is "one to which

the neurotypical minority tends to respond with some degree of prejudice, misunderstanding,

discrimination, and/or oppression (often facilitated by classifying that form of neurodivergence

as a medical pathology)."

A group of people can be **neurodiverse** if some members are neurodivergent ("groups are

diverse; individuals diverge"). It would be incorrect and racist to refer to someone as racially

diverse to mean non-white, just like it would be incorrect and ableist to refer to someone as

neurodiverse to mean non-neurotypical. Both reinforce systems of oppression by implying that

there is a privileged group to which others do not belong.

Models of Disability

Ideas about disability, including which disabilities exist or not, have changed over time, as

Joseph Straus points out in his introduction to *Extraordinary Measures: Disability in Music*:

> Disability may at first appear inescapably, solidly real—a medically, scientifically,
>
> biologically verifiable defect in mind or body. But despite its undeniable material reality,
>
> disability is also shaped and given meaning by culture. Attitudes toward disability vary
>
> with time and place and so, therefore, does the lived reality of disability. Even the sorts of
>
> conditions that are considered disabilities change with time and place. This is particularly
>
> evident in the psychiatric or cognitive domain. Some disabilities that were once felt as

entirely real exist no longer (e.g., hysteria, neurasthenia, fugue, or nostalgia—all once

legitimate, medical diagnoses), whereas others that never existed before as distinct

entities now seem all too pervasively real (e.g., attention deficit disorder or autism).[26]

In the West over the last few hundred years there have been at least four models of disability:

1) disability as a divine punishment; 2) disability as a divine gift; 3) disability as a medical defect

possessed by an individual; and 4) disability as a social and cultural construction. While the first

two models still exist today, they became much less common after the Enlightenment, which

caused the rise of the third, or medical, model. Its primary feature is the pathologizing of

disability, which associates disability with disease. The goal then becomes normalization, ideally

through a cure, with patients passively receiving treatment administered by medical

professionals. Whole institutions and professions sprang up around this model, featuring

elements of education and care, but also separation and control. Many still exist today in one

form or another, and their survival depends upon this model remaining the dominant one.

The fourth, or social, model is based on three dichotomies, as outlined by Tom Shakespeare

in his chapter "The Social Model of Disability" from *The Disability Studies Reader*: 1)

impairment is distinguished from disability; 2) the social model is distinguished from the

medical model; and 3) disabled people are distinguished from non-disabled people. An

impairment is a physiological difference that is possessed by an individual and diminishes some

function, ability, or quality of their body. It only becomes a disability when society disables that

person because of their impairment. This draws on feminism and the difference between

biological sex and social gender; ideas about gender have changed over time and differ between

cultures. Whereas the medical model only sees the deficits caused by an impairment and seeks to

prevent, cure, or rehabilitate them, the social model recognizes the "social oppression, cultural discourse, and environmental barriers" that disable. Specifically:

> Disabled people are an oppressed group, and often non-disabled people and organizations—such as professionals and charities—are the causes or contributors to that oppression. Civil rights, rather than charity or pity, are the way to solve the disability problem. Organizations and services controlled and run by disabled people provide the most appropriate solutions. Research accountable to, and preferably done by, disabled people offers the best insights.[27]

While the social model has been effective politically, instrumentally, and psychologically for disabled people, in its purest form it discounts the serious and adverse health effects caused by some impairments (possibly even rejecting science and medicine), overlooks the difficulty of untangling impairment and disability in practice, and assumes that a completely and constantly barrier-free world for everyone is possible. Like any belief, the more extreme it is taken, the more detached from reality it becomes.

The Disability Rights movement that the social model was born from has drawn comparisons to other civil rights and liberation movements, but the key difference is that "there is nothing intrinsically problematic about being female or having a different sexual orientation, or a different skin pigmentation or body shape. These other experiences are about wrongful limitation of negative freedom."[28] Many forms of impairment will remain a disadvantage no matter what barriers are removed and require society to spend extra resources (not just eliminate discrimination), and it is harder to celebrate and take pride in disability when it refers to limitations, oppression, or both.

Functioning Labels

The original version of the spectrum expanded Autism from a single, narrow diagnosis ("classic" Autism) to include a broader range, such as Asperger's syndrome and Pervasive Developmental Disorder-Not Otherwise Specified. It has since been updated because the borders between each could never clearly be defined. There is now again a single diagnosis (Autism Spectrum Disorder), but it has four different levels which are essentially separated by severity. This is the problem with the spectrum; in practice, it has been a linear path that goes from less to more Autistic.

It has been broken down even further into only two buckets for the sake of convenience: "high functioning" and "low functioning." These labels are outdated, unhelpful, and at their base level reduce people to "human doings" instead of human beings because they separate by what one can or cannot do rather than who they are. Some "high functioning" Autistics can struggle to keep up with basic life skills like good hygiene, and some "low functioning" Autistics can verbalize even if they are non-speaking. Those who use these terms are usually trying to indicate the presence or absence of intellectual impairment.

Amy Sequenzia, who has been labeled "low functioning" because she is non-speaking and requires the support of an aide for everyday tasks, touches on this topic multiple times in her contributions to *Loud Hands: Autistic People, Speaking*, an anthology of writings by Autistics published in 2012 by the Autistic Self Advocacy Network.[29] The main problem with functioning labels is exactly why they are used: they assign expectations. Essentially, is this person expected to succeed in life or not?[30] In its cruelest form, this assignment is made based on outward appearances alone.

If you are like Sequenzia, words like "hopeless," "tragedy," and "broken" might be spoken about you, but rarely to you, out of politeness or the belief that because you cannot speak you also cannot understand speech. You do not have any hidden abilities.[31]

If you are like me, you might not be "Autistic enough," "have it easy," or need to "get over it."[32] The better you are at being able to hide your impairment, the more often that you should. The fact that you can means that you do not really need accommodations because you are not really disabled.

Such discreditation tactics are used against a perceived threat to the status quo, such as a civil rights or liberation movement. These tactics include denying that the group's representatives are members of, or have anything in common with, the group that they are representing, claiming that no member of the group understands the whole situation or knows what is best, and generating stigma around membership in the group.[33]

All of this results in fear (of backlash and of not meeting expectations), which can lead to what is commonly referred to as "imposter syndrome." This prevents neurodivergent people from seeing themselves as disabled, joining that community, and seeking support. Penni Winter's essay in *Loud Hands* provides an example:

> I have spent decades of my own life straining to make myself over into that elusive "normal," and hating myself for not succeeding. I saw myself as "less than" others, furiously lashing myself for my—as I saw it—weakness and stupidity. I lived with chronic depression, overwhelming anxiety levels, and rock-bottom self-esteem. The more normal I tried to be, the less normal I secretly felt—and the more of a failure. Even when I was able to "pass," I lived with what I now call "imposter anxiety," the fear of being exposed and rejected—"You're not normal!"[34]

Instead of imagining the spectrum (for Autism or neurodiversity) as a linear slide or bell-curve, it is better to envision a circular color spectrum, with each color representing a different ability, like red for executive functioning and blue for motor skills.[35] Everyone, disabled or not, has every color, but our shades differ. Society was built around the shades shared by the most people, and together they form a certain (able-bodied/neurotypical) palette that everyone's individual palette is compared against. A person's shades can also change, gradually or suddenly, temporarily or permanently, and because of stress, age, practice, accommodation, or accident.

Conclusion

There is a dearth of scholarly writing about neurodiversity in information studies and music, and most of what does exist suffers from two major weaknesses: authorship and scope. Disability and individual neurominorities have not been neglected, though; both LISS and RILM return many more results when you search for "Autism," for example. However, as Lawrence found, most are based on the medical model of disability, exclusively use person-first language, and focus on neurodivergent children as subjects and neurotypical adults as readers.[36]

While all the results mentioned neurodiversity, they tended to focus on a single form—Autism. The neurodiversity movement came out of the Autism Rights movement and Autistic self-advocates continue to champion it, but problems persist like the misunderstanding that neurotypical means non-Autistic. Autistics need to keep promoting neurodiversity, in particular among other neurominorities, so that the people speaking and writing about the subject are not only neurotypical or Autistics.

Of the 28 total results, only two have credited neurodivergent authors. The other writers fall somewhere between neurotypicals who self-identify as having disabled/neurodivergent offspring/family members, and those who seem to have no connection to the subject at all

besides a research interest. This includes a music therapist who says that they are "considered an ally within the autistic community," like that is supposed to be a form of identification. Even if it was, it is not good enough. There is no substitute for self-advocates, who should have the same opportunities available to them (plus accommodations that allow them to be successful).

Allies are appreciated and necessary, and some like Eng and Bakan have promoted the voices of neurodivergent people and not just their own, but self-advocates should not only be heard when an advocate is amplifying their voice. We need to be the ones leading, either independently or in equal partnership with neurotypicals. This conversation is about us and we will not accept that our participation is conditional based on good behavior. "Nothing about us without us" and "loud hands" are our rallying cries for this reason.

Notes

[1] Neil Lerner and Joseph N. Straus, "Introduction: Theorizing Disability in Music," in *Sounding Off: Theorizing Disability in Music*, by Neil Lerner and Joseph N. Straus (New York, NY; Abingdon, UK: Routledge, 2006), 1–10.

[2] Dave Headlam, "Learning to Hear Autistically," in *Sounding Off: Theorizing Disability in Music*, by Neil Lerner and Joseph N. Straus (New York, NY; Abingdon, UK: Routledge, 2006), 109–20.

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