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Nava Bahrampour Bard High School Early College Queens

Jess deCourcy Hinds Bard High School Early College Queens

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Neurodiverse Navigation and Disability Equity in a NYC DoE Early College Library

by Nava Bahrampour and Jess deCourcy Hinds (Reviewed by Dr. Stephanie Kadison)

Abstract

The Bard High School Early College Queens (BHSEC Q) serves high school students who are simultaneously earning college associates degrees. The library works in partnership with a student affinity group called the Abled-Disabled Alliance (ADA). During the 2021-22 school year, the ADA has recommended a library renovation and a disability studies course, among other initiatives. The librarian taught "Disability and Equity in the Library," to 13 students, many of whom identified as neurodiverse or disabled, and invited them to reflect on their learning needs. The course culminated in research-based proposals to redesign library space and services. This work complements one of our student ADA leaders' citywide advocacy efforts in special education.

Keywords

Disability, neurodiversity, participatory design, sensory rooms, social-emotional learning, affinity groups

Biographies

Nava Bahrampour is a Year Two college student at Bard High School Early College Queens . She is also the student appointee on the Citywide Council on Special Education, and member of the Chancellor's Student Advisory Council collaborating on a policy push to expand sensory and social-emotional learning initiatives and facilities. She has served as a TA in college classes at BHSEC Q, and is the founding editor of *Neuro Nurture*, a journal by and for the neurodiverse community that will soon be available online.

Jess deCourcy Hinds is the founding Library Director of BHSEC Q, and a faculty support member of the Abled-Disabled Alliance and SAGA (Sexuality and Gender Alliance). She is also an adjunct faculty member at The Graduate School of Library and Information Science at Queens College, CUNY and a freelance writer specializing in gender and literacy. She has published creative work in such outlets as *The New York Times*, Insider and Literary Hub and has recently completed a novel.

Dr. Stephanie Kadison., PhD, is a Science Faculty member at BHSEC Q. She holds a BS in Neuroscience from Brandeis University, a PhD in Neuroscience from Albert Einstein College of Medicine, and was the Hartwell Postdoctoral Fellow at the University of Michigan. She mentored students in the Undergraduate Research Opportunity Program (UROP) at the University of Michigan; mentored graduate students at Weill Cornell; and taught genetics curriculum in the New York Academy of Science STEM afterschool program to middle school students. Publications have appeared in the *Journal of Comparative Neurology; Journal of* *Neuroscience*; *Developmental Biology*; and as a chapter in the textbook *Principles of Developmental Genetics*. Research interests include neural crest specification; axon guidance; and neuromuscular junction formation. Fellowships include: Math for America Master Teacher Fellowship (2017-present) and Sci-ed Innovator Fellowship (2019).

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Introduction

The Bard High School Early Colleges (BHSECs) in New York City are partnerships between the Department of Education (DoE) and Bard College in upstate NY. We are innovators in education with a free college associates program that provides access to higher education, and we also have campuses in Washington DC, Baltimore, Cleveland and New Orleans. At the New York City (NYC)-based BHSEC campuses, "we offer our students two years of a college preparatory high school curriculum in the 9th and 10th grades. During the final two years at BHSEC, our students are enrolled in our early college program rather than in 11th and 12th grades. BHSEC students take college courses and are offered intellectual challenges equivalent to those found on leading college campuses across the country." (Welcome to Bard High School Early College Queens). When the BHSEC Queens campus was founded in 2008, our emphasis was on recruiting bright, motivated students who would be the first in their families to attend college, and to provide a close-knit and supportive community. Most teachers at BHSEC hold PhDs and are working scholars or artists. In 2015, our program expanded to weave Special Education into these original goals, and we now have nine SpEd teachers and one coordinator. In 2017, a group of students formed the Abled-Disabled Alliance, and our school became the first in the NYC DoE to register for official recognition as a disability-related affinity group. Our disability studies course, and disabled writers' series have offered participatory design opportunities (Young, Brownotter, 2018), reflect our leadership as an early college that supports inclusive education. Throughout this paper, we will use identity-first language (LeDuc, 2015) referring to students as "disabled students" rather than "student with a disability." Some members of our community might choose to identify as "differently abled," or having "learning differences," but for the purposes of this paper, we will refer to the population we are serving as disabled, neurodiverse or neurodivergent. According to Dr. Amanda Kirby (2021), neurodivergence encompasses many traits, including autism, ADHD, mental illness and anxiety that manifest differently among individuals.

How Can a Library Support All Learners?

At the start of the 2021-22 school year, the librarian noticed two distinct changes on campus: 1. Heightened anxiety and increased vulnerability among all students—and especially disabled students—due to the COVID-19 pandemic, and 2. Students expressed more candor about their mental and emotional states and struggles and spoke about their neurodiversity with newfound pride.

On the first day back in the library in person, a student approached the circulation desk with a smile. "Do you have *NeuroTribes*?" the student asked. "I'm neurodivergent." The student hadn't even told the library staff her name before disclosing this piece of her identity puzzle. Students credit social media for destigmatizing neurodivergence.

"Can I put the book on hold?" her friend asked, and the librarian soon wrote up a waitlist for Steve Silberman's thick tome, *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity* (2015).

Since 2018, the library director has consulted with the students and her faculty co-advisor of ADA about how to make the library accessible for students with physical disabilities. But until the fall of 2021, we had not considered what adaptations we might make to support psychological and neurological health. The increased awareness about neurodiversity and heightened focus on Social-Emotional Learning (SEL) lent urgency to this project. Our library is relatively small for a college library; approximately 1,500 square feet with two separate multipurpose tutoring rooms. It has a standard library design, with stacks over six feet tall that not all bodies can access. Our collection is primarily print and digital. Although we have connected to the New York Public Library audio collections and Sora, a free e-book initiative for the DoE, our use of audiobooks is limited. The library also lacks sensory spaces and areas where students with autism can stim or experience sensory catharsis. With a new population identifying as neurodiverse, the library staff knew we needed audiobooks and sensory spaces.

The Role of the ADA in the Library

Affinity groups are groups of individuals with a social identity in common, often an identity related to gender, race or disability. These groups often join together for the purpose of diversity, equity and inclusion in a workplace for school. (Syracuse University). At BHSEC Q, our affinity groups provide support, advocacy and they work to spread awareness across the community. In the ADA, allies of the disabled community, including people with family members or friends who identify as disabled, are welcome. We recognize that covert and overt ableism and social exclusion of people with disabilities can go unnoticed. Therefore, our group helps disabled and neurodiverse students to connect with one another and find supportive mentors. The library is a space where neurodiverse students often flourish because it is socially inclusive and welcoming of students with sustained interests and passions, as many students with autism have. Creating a socially inclusive space outside the classroom is vital for students' mental health and confidence. Students with disabilities of various types are more likely to experience social exclusion than neurotypical and able-bodied students, simply because our conventional social structures, especially in schools, are rooted in ableism.

For example, the notion that there is one way for someone to present oneself when meeting new people and a strict list of norms that they should avoid deviating from makes it more difficult for some students who struggle with sensory (including visual-spatial), social, and emotional cues to fit into the social practices and feel included. This can lead to mental health struggles later on. For example, a neurodivergent student might feel as if they have to adhere to norms that are naturally more difficult for them than for their neurotypical peers, which can lead to increased anxiety and behavior known as 'masking.' Masking is widely defined as the suppression of neurodivergent traits in order to conform and be accepted into a neurotypical social environment. Masking can lead to burnout and depression, and if we create spaces where we celebrate neurodiversity and discuss disability openly, students who are neurodivergent will feel less of a need to suppress the traits that are natural to who they are. The ADA cultivates an environment

in which students feel more comfortable discussing disability, inclusion and issues of ableism in their institution.

Because the librarian is one of the faculty advisors, and we meet in the library, much of our work centers in this space. The library is a refuge and a center for study, research and community for many students. We want to ensure that neurodivergent and disabled students can fully benefit from all of the library resources. During our meetings, students have made suggestions for showcasing disability-themed book displays, encouraging the library to showcase more entertaining texts rather than academic ones. For example, we displayed Emily Landau's welcoming book, *Demystifying Disability: What to Know, What to Say, and How to Be an Ally* (2021) and Keah Brown's 2019 memoir *The Pretty One: On Pop Culture, Disability and Other Reasons to Fall in Love with Me.* Both books have colorful, eye-catching covers and are entertaining to read.

Finally, we reviewed the librarian's Disabled Writer series and made lists of the genres of fiction we'd like to see represented in the series (such as romance and fantasy). The series currently includes blind authors M. Leona Godin and James Tate Hill, deaf poet and journalist Sara Katz, and Amanda LeDuc, who has Cerebral Palsy. The series will expand to include neurodivergent authors, and we are looking to build more intersectionality into the series in the future. The ADA also proposed changes in disability terminology on course syllabi, and has drafted emails to faculty to make requests for how they discuss accommodations. These emails will go through administrative approval before being sent out the first week of school. The ADA would also like to offer professional development to teachers about how their experiences as disabled students could be improved. The ADA also offered a successful anti-ableist poster campaign with messages such as, "Disability Is Not a Dirty Word," and "Do You See Me or Do You See My I.E.P.?" (for Individual Education Plan).

When the ADA requested that the school offer a disability studies course, we designed it to dovetail with the renovation project. The 13 students who registered for the course joined the ADA as researchers and collaborators.

Disability Studies and Participatory Design

The erasure of neurodivergent students is prevalent in most traditional school curricula, so the addition of a disability studies course was an important step towards diversity, equity and inclusion at our campus. Here is the course description for the college elective course: Disability and Equity - 1 credit

In this course, students research within the fields of education and library science to explore how schools and libraries support the needs of all learners. We will consider both the physical and emotional needs of students. Drawing on the works of disability theorists, trauma-informed teaching in the COVID era, students will design, research and implement projects to enhance accessibility and equity in the library. Students will actively participate in planning several plans to redesign the library space for learning equity.

Our disability studies course draws on the theory of participatory design. According to Young and Brownotter (2018), the tenets of participatory design include:

- Shared power
- Equal Expertise
- Mutual Learning

- Co-creation and determination
- Democracy

Disabled and neurodiverse students have a wealth of knowledge, experience and insight about their needs and experiences. Able-bodied administrators, teachers and librarians cannot design schools without having these voices centralized. Therefore, participatory design gives students a voice in decision-making and role designing the spaces and resources they use. Early in the course, students took a walking tour of the library with cameras and sketchpads, and identified areas for improvement. After students made recommendations, they conducted research using databases such as JSTOR, ERIC, and Academic Search Premier to learn about the conditions they aimed to support. Students researched Dyslexia, ADHD, anxiety, print disability, blindness and other conditions.

To support neurodiversity and anxiety, students recommended removing or reducing the intimidating stacks, and bringing the focus of the library closer to the floor. They suggested curved shelves or coves for privacy and to reduce stimulation and feelings of being overwhelmed, floor cushions or bean bags. Many students commented on the study carrels we already owned, and spoke positively about the way the wooden dividers helped students reduce overstimulation and focus on their work.

Numerous students suggested dimming the harsh fluorescent lightning and providing fidget toys like squeeze balls or a small bin of sensory beads. Noise-muffling headphones would create complete silence for students for whom the creaking of a chair or even breathing of another student could be distracting. A room might include a "crash pads" where students with autism or sensory overload can run and jump onto a soft surface when overwhelmed. One library patron in our community with autism runs in a circle in the center of the library space before sitting down abruptly. A crash pad in a separate room would be safer and more supportive to her. Rocking chairs and sway chairs would also assist students who cannot stay still for long, or those who require vestibular stimulation to study.

Students' proposals also included Multisensory Environments (Stephenson, 2011) that would include a wide range of light and sound effects that help students self-soothe and focus. Sensory rooms can include light projection similar to a lava lamp, waterfall or a bubble tube, and vibration and sound for soothing. Many neurodivergent students require these tools to feel the coherent sense of self that a neurotypical person might take for granted. "Sense of self implies a basic spatial unity of the self and the physical body. To generate a unified self, the brain must bind together different sensory inputs linked to different body parts." (Slater et al., 2010). Multisensory environments help students find this physical and mental unity.

Citywide Activism for Inclusive Libraries/Classrooms

Initiatives for academic, social and sensory inclusion are best implemented through large-scale, citywide policy change. Various education councils like the Education Council Consortium and student groups like the Chancellor's Student Advisory Council are influential in pushing inclusive policy on behalf of students and stakeholders. The NYC DoE Special Education office seeks student and parent opinions in order to make decisions about citywide special education services. We are fortunate that one of our student members of the ADA works on these citywide initiatives, giving the affinity group a bird's eye view of change in Special Education, and helping connect our school to exemplary programs and initiatives.

One of our ADA members has shared stories of her work with the Sensory Exploration, Education and Discovery (SEED) initiative. SEED is a <u>NYC DoE Special Education Recovery</u> <u>Service</u> in which students who require individualized sensory instruction are provided with the opportunity to work with occupational and physical therapists at facilities around the city. There is also a social-emotional component – SEED providers frequently check in with their students in order to gain knowledge on how they are feeling and help them gain knowledge of their own emotional state and how to change and improve it. At SEED sites, sensory and literacy education can be combined. In a session that our student leader attended, a volunteer guided a student to play a word game while the student swung gently on a wooden swing. The student spelled a word with beanbag letters as they swung. SEED will be expanding in the years to come due to policy pushing from Citywide Council on Special Education members and families who have greatly benefited from the program.

This is relevant when considering library accessibility because a program like this sensory and literacy initiative will also have the potential to reach thousands of students who use school libraries across the city. A collaboration between the NYC DoE and City University of New York will ensure a seamless transition from high school to college for all students. This summer, our library will install two <u>reading coves</u> to create a distraction-limiting, sensory friendly audiovisual center with iPads, charging stations and headphones for listening and blocking out sound. The reading coves are wheelchair accessible and display books at eye level. We will house the collections of affinity groups, from the Black Lives Matter Task Force to the Muslim Student Association to the ADA, so that the reading cove area centralizes student voice. Throughout the school year, we will build the sensory room and add rockers and sway lounge chairs to the main library space.

Many neurodivergent students' learning styles are not widely represented throughout the curricula and physical design of our schools. It is time to add sensory and social-emotional education to the discussion of what students need in libraries and classrooms. Let's all invite our disabled and neurodivergent students to participate, create, collaborate—and lead the way toward true social and educational inclusion in all library and learning spaces.

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Welcome to Bard High School Early College Queens. https://bhsec.bard.edu/queens/