

Laying the Foundation: Actionable Steps for Establishing a University Center for Neurodiversity (Practice Brief)

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Abstract

Educating higher education communities through a cultural understanding of neurodiversity has the potential to reduce stigma and ableism faced by neurodivergent people and to support understanding of neurodivergence as valued diversity. Embracing neurodivergence through a cultural understanding of neurodiversity is important for neurodivergent college students in the process of their own identity development. Unfortunately, limited understanding and/or resources have impeded the development of neurodiversity cultural centers on most university campuses. The present article details actionable steps one university took to launch a university center for neurodiversity. Shared actions may support others toward neurodiversity cultural center development, and include development of a whitepaper, learning from other universities with cultural centers, developing clear aims, establishing a participatory leadership structure, and obtaining accessible space. Suggestions in this article can be adjusted and adapted to the unique needs of other university communities, with a focus on engagement around neurodiversity. Recommendations are provided for a multitude of leadership positions that can be combined based on resources and needs.

Keywords: neurodiversity; cultural center; university; college; diversity

The term neurodiversity refers to neurocognitive differences that are naturally occurring within our population. Recognizing natural variation as valuable, the neurodiversity paradigm is associated with the perspective that a diversity of minds, brains, and bodies benefits society (Walker, 2021). Disability labels commonly associated with neurodivergence include autism, attention deficit disorder, dyslexia, Tourette syndrome, and mental health conditions. However, neurodivergence is a cultural identity, not a disability label, and people identifying as neurodivergent may or may not also identify as disabled (den Houting, 2019).

Historically, neurodivergent people have been excluded from higher education (Hamilton & Petty, 2023) and a focus on remedying this exclusion has been absent from higher education social justice initiatives (Hughes, 2016). Neurodivergent students who do attend higher education routinely face systemic ableism (Dolmage, 2017; Janse van Rensburg

& Liang, 2023) and disability-related prejudice and stigma (Dwyer et al., 2023). The neurodiversity movement, which began with the autism rights movement, redefines neurodivergence from a strength perspective providing a framework to eliminate prejudice and stigma surrounding disability and difference (Kapp, 2020).

With leadership from autistic self-advocates and the neurodiversity movement, recommendations are emerging to support neurodivergent people, including students, faculty, and staff in higher education (e.g. see Dwyer et al., 2023; Hamilton & Petty, 2023), and research to understand the experiences of neurodivergent people in higher education (e.g. see Cox et al., 2021; Mellifont, 2023). Primary recommendations to support neurodivergent students, faculty, and staff include expanding social justice initiatives to embrace neurodiversity, broadening equity and inclusion initiatives beyond race and gender (Hughes, 2016; Kuder et al., 2021) and establishing disability cultural centers

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(Dwyer et al., 2023; Saia, 2022). Such initiatives support the socially constructed labels of neurodivergent and/or disabled as positive cultural identities.

Depiction of the Problem

Educating higher education communities through a cultural understanding of neurodiversity has the potential to reduce stigma and ableism faced by neurodivergent people and to support understanding of neurodivergence as valued diversity. Such understanding is important for students to form positive identities of self and to feel pride around neurodivergence and disability (Shmulsky et al., 2021). While not all people identifying as neurodivergent identify as disabled, university structures overwhelmingly require students to disclose a disability identity to receive accommodations and supports in higher education. This requirement further stigmatizes neurodivergent people, and facing pervasive stigma leads to internalized negative views of self (Gurba et al., 2024). Cultural center affiliation may support neurodivergent college students commonly grappling with positive identity development, as affiliation with peers with similar life experiences strengthens feelings of pride (Nachman, 2023). Unfortunately, limited resources and funding are available to support the development of cultural centers on most university campuses (Chiang, 2020).

While a limited understanding of neurodiversity permeates higher education communities (Castleman et al., 2024), neurodivergent students are increasingly attending colleges and universities, albeit without the support systems provided to other minoritized groups. A cultural understanding of neurodiversity is needed to reframe deficit perspectives (Gobbo & Shmulsky, 2019). Building on Chiang's (2020) experiences of launching a disability cultural center with limited resources, the present article details actionable steps for launching a university center for neurodiversity. The goal of sharing our actions is to support others in developing neurodiversity (or disability) cultural centers.

Setting and Participants Demographics

Rowan University, a Carnegie-classified R-2/high research institution is located in southwestern, New Jersey. The university presently serves 23,000 students across the main campus, two medical school campuses, and five affiliated colleges. With a focus on the main campus, the office of accessibility services provides support to students with various documented disabilities in accordance with Section 504 of the Rehabilitation Act of 1973 and the Americans

with Disabilities Act (ADA) of 1990. At the time we began identifying a need for a center for neurodiversity in 2019, over 2,100 students were registered with our office of accessibility services (more than 10% of all students). Of that total, approximately 900 students identified as neurodivergent. As a university we recognized a need to build on these services to support our large neurodivergent student population. A neurodiversity affirming campus has the potential to remedy educational inequities not addressed by special education mandates alone (Gobbo & Shmulsky, 2019). In other words, understanding students through a cultural perspective and building on student strengths—moving beyond providing accessibility services based on disability labels and identified deficits—encourages student belonging and pride through affiliation with peers having similar life experiences (e.g. see Nachman, 2023).

Description of Practice

Rowan University has a strong office of accessibility services as well as a strong division of inclusive excellence, community, and belonging, and we foster a collaborative partnership between the two entities. This collaboration, coupled with a supportive charge from university leadership, provided the seeds for developing a university center for neurodiversity. A university neurodiversity taskforce was formed and led by our division of inclusive excellence, community, and belonging. The taskforce was comprised of neurodiverse (neurodivergent and neurotypical) faculty, staff, students, and community partners. Once formed, our task force split into several working groups focused on establishing a professional development course for faculty and staff around inclusive practices, and gathering student, faculty and staff feedback around neurodiversity affirming practices already provided by the university. This initial work provided a foundation for establishing our cultural center. Informed by campus community feedback, our center for neurodiversity was established in October of 2021. Below we detail foundational actions taken to launch the center that can be adjusted and adapted to the unique needs of other university communities.

Development of a Whitepaper

The initial focus was development of a neurodiversity center whitepaper—an in-depth report detailing existing issues, research, and data, and advocating for proposed solutions. Preparing the whitepaper for university leadership, members of the neurodiversity taskforce outlined the need for a center for neurodiversity to fully reach its commitment to equity and

inclusion as a university. The taskforce operationally defined neurodiversity as “the full range of variations in cognition, learning, behaving and interacting that exists among individuals,” and embraced the perspective that neurodiversity is valuable to our university campus and to the wider community. Development of a whitepaper was essential to detail the shared definition of neurodiversity, rationale, core values for the center, important shared language, specific needs, existing services and programs, and recommendations including organizational structure and resources. As indicated in the whitepaper (2019):

The proposed Center for Neurodiversity will result in a greater understanding of the intersection of race, class, and ability; enhanced services and programming based on a shared understanding of intersectionality; normalizing access to accommodations and modifications that result in student success; strengthening the compliance aspect of the office through close collaboration with the office of student equity and compliance; and strengthening the message that neurodiversity is an important aspect of diversity that requires a commitment to equity and inclusion.

Learning from Critical Friends

Once the whitepaper was affirmed by university leadership, a key aspect of success can be attributed to learning from other universities and colleges with cultural centers. Landmark College, the University of LaVerne, and William and Mary University are just a few initial leaders in establishing neurodiversity cultural centers. Engaging with multiple institutions via video calls, email, and phone calls allowed for practical question and answer sessions and troubleshooting. Developing a table of the values of other university centers and their mission statements also helped the taskforce home in on its own distinct aims (See Table 1).

Developing Clear Aims

Having clear aims, including a vision and mission, is key to the work of a center. Upon the launch of the center, the taskforce received many requests that fell outside of our aims. Clear aims provided guidelines to navigate and decline these requests with clarity. Similarly, having clear aims as well as a vision and mission provided a structure for focusing on the needs most relevant to the university. The taskforce established aims clearly as (a) centering neurodiversity in university equity and inclusion initiatives, and (b) valuing and prioritizing neurodiversity culture. In alignment with these aims, the taskforce developed

related statements to introduce the center to the wider campus community:

The Center for Neurodiversity provides programming, research, and community engagement that value and prioritize neurodiversity culture. The Center for Neurodiversity defines neurodiversity culture as group belonging and pride formed around shared lived experiences, personal dis/ability identity, and social justice activism.

Programming: We provide programming, events and professional development that present neurodiversity through a strengths-based lens, with a focus on education and social justice.

Research: We conduct research prioritized by the neurodiversity community including participatory research that furthers autonomy and opportunity for neurodivergent people.

Community Engagement: We encourage engagement with students, educators, and families in the surrounding communities around neurodiversity culture, needs and initiatives.

We established our overarching vision and mission as follows:

Our Mission: Providing programming, research and community engagement that value and prioritize neurodiversity culture.

Our Vision: A fully inclusive community with meaningful participation for all (Center website 2021-2025).

Establishing a Participatory Leadership Structure

Through data gathering and conversations with other universities, a primary obstacle to launching a cultural center was as a lack of resources to support faculty/personnel leadership. With that obstacle in mind, potential year one and two leadership positions that evolved and supported the center’s growth are detailed here. This section is meant to provide multiple paths to establishing center leadership. Note that priority to placing neurodivergent people within this leadership structure aligns with a vision to prioritize and value neurodiversity culture.

Faculty Director

It is important to note that the center’s leadership structure has evolved over time. Initially, in lieu of a large salary expenditure, a year one faculty director position can be “half time” and filled via a six credit per semester release agreed upon by university lead-

Table 1*University Centers and Initiatives as Resources*

	Mission/ Purpose	Values	Access
Landmark College Center for Neurodiversity	To advance an understanding of the benefits of a neurodiverse society.	We believe that brain-based diversity should be understood as normal, beneficial, and essential for human progress. Neurodivergent people should be included in all endeavors about them. Neurodivergence is linked to exceptionality and disability. Both are important to recognize.	 https://www.landmark.edu/center-for-neurodiversity
University of LaVerne Center for Neurodiversity, Learning & Wellness	To create transformative learning experiences that inspire students, educators, families, and community leaders to value neurodiversity and maximize our human potential.	We value the lived experiences of neurodivergent learners by giving voice to their needs and unique worldview. We are committed to redefining special education at the highest levels and seek to address the spirit of the learner before the diagnosis.	 https://www.laverne.edu/news/2018/08/09/
Rowan University Center for Neurodiversity	To provide programming, research and community engagement that value and prioritize neurodiversity culture.	We value neurological differences as diversity and as one of many aspects of identity, recognizing that a variety of minds benefits society, viewing neurodivergence from a strength perspective, and understanding that neurodiversity and disability co-exist.	 https://sites.rowan.edu/neurodiversity/
Stanford School of Medicine Stanford Neurodiversity Project & Stanford University Summit	Project: To establish a culture that treasures the strengths of neurodiverse individuals. To empower neurodiverse individuals to build their identity and enhance their long-term skills of daily living throughout the lifespan.	Summit: Exchange of ideas about neurodiversity among all people. (The Summit) is a venue where we listen to each other, especially when our views are not the same. This active listening is not just about respect, but an act to grow together as a community. At this forum, we will share visions, innovations, and inspirations about how neurodiversity can make our society better.	 https://med.stanford.edu/neurodiversity.html
William & Mary The Neurodiversity Initiative	Seeks first to serve our campus community and ultimately to be a model for other campuses. The Neurodiversity Working Group organizes campus events and programs in support of the Neurodiversity Initiative.	We are committed to educating our campus community about brain differences, and to supporting and cultivating an appreciation of the many kinds of diversity we can nurture at our historic institution.	 https://www.wm.edu/sites/neurodiversity/

Note. Table content includes direct excerpts taken from the websites indicated, retrieved 12/12/24.

ership. This adjusted teaching load provides the faculty member with time to take on center leadership. The faculty director responsibilities include overseeing the day-to-day operations of the center, developing and carrying out the center vision and mission, and developing leadership and direction for the center that address the established aims.

Graduate Coordinator(s)

Designating a PhD student via a fellowship to the center for neurodiversity may be possible at research intensive institutions. It is recommended that this PhD student/graduate coordinator provide support and assistance in the development and implementation of actionable progress toward aims. The graduate coordinator(s) should work with and assist the faculty director in day-to-day operations while learning from the faculty director in a mentor/mentee relationship. The position should be temporary and filled for one to three years in alignment with PhD student fellowship norms.

Center Greeters

The federal work study (FWS) program is a program provided by the Department of Education to support students in financial need with up to 20 hours of work per week. Applying for two FWS students provided the center with a means to hire neurodivergent students in need of employment and expend limited center resources. While the primary responsibility of each center greeter was to be a welcoming support to patrons, the center found its FWS students to be especially savvy in designing flyers and in developing and posting social media announcements to support center events and happenings.

Faculty Fellows

In addition to release time for the faculty director, university leadership initially supported release time for two faculty fellows to the center for neurodiversity, each receiving three credits release time. Based on center needs, one faculty fellow was student support centered and one faculty professional development centered. Faculty affiliation with the center also fostered strong connections with various colleges and departments.

Neurodivergent Student Advisory Board (internal)

With a focus on developing advocacy, a neurodivergent student advisory board was established, with board members in service positions. Our initial neurodivergent student advisory board included 5-10 students who advised leadership on student needs and established priorities, and contributed to the center's

overall mission of prioritizing and valuing neurodiversity culture. Student advisory board members committed to attending structured advisory board meetings each semester and providing ongoing communication via a choice of communication modalities. Paid opportunities were prioritized for this group when available, such as opportunities to host question and answer sessions with guest speakers. Such a board should be updated on an ongoing basis with interested neurodivergent students added to the board and recent graduates removed from the board annually.

University Steering Committee (internal)

A center for neurodiversity steering committee formed out of our original neurodiversity task force. Such a committee should include a neurodiverse group of faculty, staff, students, and alumni providing recommendations to the center's overall mission. The center found success in asking steering committee members to commit to serving on one actionable committee each semester related to center aims. Considered university service, members participated through meetings held each semester, as well as ongoing communication and work toward committee deliverables.

Neurodivergent Scholar in Residence

In year two, the center was approved to hire a scholar in residence. Having a neurodivergent scholar affiliated with our university was instrumental in guiding future decision-making and student support. Responsibilities of a scholar in this paid position should include guiding the center programming and events, supporting neurodivergent students as an expert and role model, educating the wider campus community around neurodiversity, and supporting curriculum redevelopment and use of Universal Design.

National Advisory Board (external)

In year three, the center established a national advisory board. A national advisory board should be appointed by the faculty director and comprised of alumni, community leaders, neurodivergent scholars, and faculty/staff who identify as disability self-advocates and/or experts. Members should be invited to serve on a two- or three-year term (to avoid all members changing year two). A new center is likely to benefit from the expertise and insight of national board members who represent the wider neurodiversity community, share expertise in the area of postsecondary education and neurodiversity, and provide focus as a cultural center. The advisory board members should attend one meeting per semester, and broaden the reach of the center, including toward new donors.

Program Manager

A long-term goal of hiring a paid program manager to serve in the role of center oversight, assisting the faculty director of the center, pending available funding, is recommended. This program manager can serve as point person in the faculty director's absence. Program manager responsibilities should include oversight of facilitates, interaction with students and student groups, coordination of center initiatives and center operations and initiatives.

Obtain Accessible Space

While one primary obstacle to launching a cultural center is a lack of resources for faculty/personnel for leadership, the second obstacle is that of space. Obtaining space for neurodivergent campus community members to engage with one another is also the primary non-negotiable when obtaining initial resources. While space is essential, it does not need to be large. It does, however, require team engagement around space needs and planning. For example, Chiang (2020) shares the experience of successfully establishing a disability cultural center on the University of North Carolina Asheville's campus with limited resources using a spare room in an academic building. Rowan's opportunity was to use a series of small rooms in a building historically used as a dormitory. To date, this space has worked quite well after overcoming initial hurdles, such as the need to reallocate limited year one resources to adding an accessible door at the building entry. These experiences illustrate the need to emphasize flexibility, as waiting for perfect space may not be an option and in many cases may result in a cultural center not launching at all.

Once physical space is obtained, engagement with neurodivergent students, faculty, and staff should be emphasized to design its usage. After having students put together a wish list, the center was able to get small donations of items to create a sensory friendly and comfortable space, including noise reducing wall panels, dimmable floor lamps, a white noise machine, floor cushions, and games and puzzles. Additional donations included gently used furniture from university housing, such as a sofa and game table. This sensory friendly space, as well as a meeting room and welcome area, are now the hub of the center.

Evaluation of Observed Outcomes

Since the launch of the Center for Neurodiversity in 2021, Engaging in participatory continuous improvement has been a norm. During a two-year period, from 2021-2023, faculty, staff, and students were invited to share their perspectives around neuro-

diversity culture on campus, through a survey, focus groups, and one-on-one interviews. Critical feedback for continuous improvement obtained through data collection included recommendations to prioritize initiatives that value neurodivergent students (e.g., to build on affinity groups and sensory friendly spaces), to simplify the processes to receive neurodiversity affirming supports, to expand supports for mental health, and to increase faculty/staff professional development around Universal Design and neurodiversity (see Accardo et al., 2024). This critical feedback continues to guide the center's work.

Implications and Transferability

The needs and experiences at Rowan University may not be identical to other universities, however the extant literature has established that (a) a focus on neurodiversity is largely missing from university equity and inclusion initiatives, and (b) redefining neurodiversity through a cultural lens supports neurodivergent students, faculty, and staff (Dwyer et al., 2023; Saia, 2022). The value of neurodiversity and the experiences of disabled people have been positioned as taboo topics through a lack of attention, conversation, and education throughout history. In light of the current political tensions and pushbacks against DEI initiatives, leadership, conversation, and understanding around neurodiversity are more important than ever. Suggestions in this article can be adjusted and adapted to the unique needs of other university communities, with a shared focus on engagement around neurodiversity. Summarized here are three initial actions with benefits believed to be transferable across higher education communities: (a) engage around neurodiversity with the university community (e.g. book studies, speaker series and data collection through listening tours, surveys, and interviews); (b) engage in participatory planning of the center with neurodivergent faculty, staff and students; and finally (c) engage with external experts including neurodivergent self-advocates and critical friends from universities with existing neurodiversity initiatives.

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