Autistic-Centered Program Development and Assessment Practices (Practice Brief)

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Abstract

The authors of this article invite disability and student affairs professionals to engage autistic college students and colleagues in program development and assessment efforts. Ten strategies to construct student support programs and assessment designs are provided that are inclusive of autistic students, staff, and faculty input and participation from start to finish. Recommendations by Dena, an autistic social scientist/co-author, are embedded within the strategies to provide a neurodivergent perspective. Together, these strategies are grounded in principles of community-based participatory research, neurodiversity, and autistic expertise.

Keywords: autism, disability, assessment, higher education, student affairs

Autistic students are increasingly participating in postsecondary education. While reasonable accommodations are legally mandated, autistic students may benefit from social and co-curricular supports that go beyond legally mandated accommodations (Sarrett, 2018). Disability and student affairs professionals are asked to cultivate "autism friendly" (p. 679) programs and engage in assessment to document the extent to which they effectively serve students. Here, we focus on student support programs, which are "often designed with the specific intention of ultimately improving student retention and graduation by facilitating a smoother academic and social transition" (Mayhew et al., 2016, p. 386).

Within academic organizational systems, Disability Resource Centers are responsible for providing services and programs "that promote access to the campus community" (Association on Higher Education and Disability, n.d., sec. 2.2). As such, disability and student affairs professionals serve critical roles as they create programs that promote students' self-advocacy, cultivate transferable skills, and foster disabled pride (Evans et al., 2017). Further, practitioners are responsible for assessing these programs.

Program assessment plays an important role in data-driven decision making. The purpose of assessment is to provide metrics of improvement and accountability for internal and external stakeholders (Ewell, 2009). Practitioners utilize program assessments to make decisions about resource allocation, identify programs that benefit specific groups of students, and focus on developing specific competencies (Lombardi et al., 2018). For instance, program assessment results can help orientation staff create transition programing with decompression breaks, assist residence life staff as they develop programs to support positive roommate dynamics, or encourage student activities professionals to plan events in sensory-sensitive spaces.

Depiction of the Problem

The process of program assessment is influenced by social and political contexts (Wall et al., 2014). In particular, power in assessment practices reside within the individuals who get to decide "which experiences and activities add value to a student's college experience" (Patton et al., 2015, p. 210). Abled practitioners may be unaware of phenomena that disabled students experience (e.g., crip time; Peña et al., 2018) or issues that are critical to disabled students' engagement and success (e.g., consistent access to gluten-free food in campus dining; Wilke et al., 2019). Thus, abled practitioners may overlook important assessment topics (e.g., independent living; Brown & Broido, in press) or ask adverse assessment questions.

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There is little guidance on how to develop or assess programs that are accessible to, and valid for, disabled populations (Brown & Broido, in press). As professionals are asked to develop autism-specific programs, it is important to understand the extent to which the outcomes of these activities are valid, that is they reflect the goals of autistic people themselves (Gillespie-Lynch et al., 2017). Without autistic involvement, programs are limited to neurotypical understandings of success and disability, and student affairs professionals may not recognize programmatic strengths or areas for improvement. For example, autistic students may perceive participating in an interest group as a successful activity if five other students with shared interests consistently attend the weekly meetings. However, neurotypical professionals may overlook the value of engaging with others who share interests, and simply see the group's value in relation to low attendance.

The purpose of this practice brief is to address power differentials and validity limitations in program development and assessment. Given that traditional methods of programing exclude the input of autistic people, we marry principles of community-based participatory research (CBPR; Powers, 2017), neurodiversity (Robertson & Ne'eman, 2008), and autistic expertise to outline strategies professionals can employ to build and assess programs with autistic students and colleagues.

Strategies for Autistic-Centered Program Development and Assessment

The co-authors of this article represent one abled, one autistic, and one dyslexic educator. All of us are mothers, and two of us are parents of autistic sons. Drawing on autistic studies literature, collaboratively we created 10 strategies for centering autistic students and colleagues during program development and assessment design (see Table 1). We recognize that "academia powerfully mandates ablebodiedness and ablemindedness" (Dolmage, 2017, p. 7) and academic ableism systematically limits the contributions of autistic people. Building on the work of Prince-Hughes (2002) we intentionally model neurodiverse thinking via writing practices that diverge from academic writing traditions of "following one 'logical' train of thought to what amounts to forgone conclusions" (Prince-Hughes, 2002, p. xii). Neurodiverse thinking sees multiple, non-exclusive, and often non-linear possibilities. In our presentation of strategies that follow, we embed recommendations by Dena, our co-author who identifies as autistic. While Dena's experiences as an autistic self-advocate are not meant to represent overarching views of the autistic community, her experiences and participation in the autistic self-advocacy community enables her to contribute a neurodivergent perspective. In addition, Dena's input offers a counternarrative to traditional and ableist academic rhetoric typically found in journal articles. In making this choice we hope that neurotypical readers can begin to reimagine assessment practices to fit with autistic goals.

Employ a Community-Based, Participatory Approach (CBPR)

While there are a number of ways to design programs and improve assessment efforts, one area that is overlooked in the higher education literature is the lack of inclusion of autistic students, staff, faculty, allies, or community members in this process. We draw on principles of community-based participatory research (CBPR) to overturn the traditional power imbalance between individuals who develop programs or design assessments and the community being served or studied, by no longer regarding disabled individuals as "other" but as part of the community of decision makers (Foucault, 1990; Powers, 2017). CBPR involves "power sharing by academic and community researchers, full engagement of community partners across all study phases, and ongoing commitment to partnership and capacity building" (Powers, 2017, p. 42). Dena provides an autistic perspective by describing the importance of including autistic people within the program development and assessment process.

> If autistic stakeholders are not part of program design, they will be less likely to see/maximize the benefits of the program. The phrase, "nothing about us without us," captures the idea that disabled persons are the experts on their own lives. In the United States, this phrase became the motto and advocacy cry, expanding from the broader disability community to include the autistic community with the rise of the Autistic Self-Advocacy Network (ASAN; Charlton, 2000). It continues to be used in the disability community as power imbalances and colonialism/ableism are rejected. The "nothing about us without us" mindset needs to be incorporated into any study involving outcomes and satisfaction considerations when engaging in the development or assessment of programming for autistic students.

Thus, CBPR is a tool that practitioners can use to follow the "nothing about us without us" mindset.

Develop Trusting and Respectful Relationships

Before collaborative program development or assessment design begins, disability and student affairs professionals "need to develop mutually supportive and respectful relationships with members of the autism community" (Pellicano et al., 2014, p. 1.). When developing relationships, professionals may need to initiate communication with autistic students, colleagues, and allies to build rapport by using a variety of communication formats. Trust is built within a relationship by engaging over multiple occasions. Building respectful relationships involves presuming competence and checking assumptions about autism or the ways in which autistic individuals may express themselves. Dena explains how assumptions about autistic expressions hinder relationships.

The varied and unique presentations of autism may lead to inaccurate presumptions of ability and areas of accommodations/support; challenges to competence, questioning, doubting, and/or confusion on the part of others. If the expression of autism is externalizing (obviously presenting possibly with stimming, social differences, language differences requiring technology or "translation" support) the autistic person's capacities may be underestimated. If the person's expression of autism is internalizing (less obviously presenting, minimal or use of more socially acceptable stims like foot bouncing or hair twirling, and good use of syntax even if communication is impacted) they may be subjected to proving that they are autistic over and over again (Gassner, in press). "They thus face a double bind: either they forgo the assistance or accommodation they need— thus suffer the consequences of attempting to do things they may not be able to do safely by themselves—or they endure the discomfort of subjecting themselves to strangers' interrogations" (Davis, 2005, p. 154-155). These outcomes are burdensome for autistic persons and add another layer of effort.

Given these circumstances, we recommend prolonged engagement with autistic partners. Cultivating trusting relationships and partnerships may take many months and multiple encounters. Though this may feel time-consuming to the person or team in charge of program development and assessment, the benefits of establishing a strong foundation with autistic partners are worthwhile to developing trustworthy and actionable findings.

Value Neurodiversity

Neurodiversity or "neurological pluralism" stands for disability inclusion, tribe, family, self-acceptance, and a strong refusal to deny disability (Silberman, 2015). Neurodiversity, as a paradigm, works to reframe what normal means, recognizes and values neurological differences, and honors the contributions that neurodivergent individuals make to society. Neurodiversity is a shift away from deficit-driven understandings and a term used to describe "the neurological diversity of autistic people, dyslexic people, and people with other major differences in cognitive processing" (Robertson & Ne'eman, 2008, para. 8). This paradigm inherently honors variation and denies the social construction of disability as a negative status or unwanted identity. Neurodiversity is one way the autistic community has taken back their identity, including their disability identity, by choosing their language and in doing so, stated that living with autism is not something to repress. Dena explains,

The disability office and student affairs personnel should not only respect the othered voice—they should elevate and honor it. If we are not respected, we as gatekeepers and referral sources for our community simply do not support the research, program, or assessment.

Using a neurodiverse paradigm, disability and student affairs professionals honor, respect, and value the differences in autistic knowledge and expertise.

Center the Goals of Autistic Communities

In order to develop programs and assess if that program meets the needs of autism communities, professionals must understand exactly what those needs are (e.g., fostering social interactions, supporting multiple forms of communication, or developing friendships; Sarrett, 2018). Therefore, prior to developing a program or assessing its outcomes, professionals should collaboratively engage with autistic students and community members to develop and agree on the goals of the program. Engagement with autistic communities is critical to addressing construct validity—that is the degree to which the assessment measures the construct that it is supposed to be measuring (Brown & Broido, in press). For example, an assessment of a social program that does not include metrics for sensory stimuli may not elicit tangible ways to improve students' social engagement. Dena summarizes, "everything from *how* you present the question to *what* you prioritize should begin and end with autistic student input."

Discuss Participants' Confidentiality and Privacy

The process of coming out as disabled or acting as a representative for a minoritized group involves emotional labor (Miller, 2015); thus, some autistic students may not want to have their participation be public. Further, disabled people navigate stigma, microaggressions, and discrimination by making strategic and context-specific disclosure decisions. Disability and student affairs professionals should protect privacy by providing the option to confidentially participate in program design and assessment. If confidentiality is not possible, professionals must ensure autistic collaborators have control over their disclosure narratives.

Although disclosure narratives could involve medical language, environmental or behavior-based descriptions offer selective information that is relevant to the program context. Dena provides an example of how behavior-based descriptions can limit public disclosure, "offer the option to say, 'student has trouble focusing in a busy room' versus a shout out that the student is autistic." Dena's example demonstrates how to place emphasis on the environment and privacy as many individuals might have difficulty focusing in a busy room, including students with ADD, ADHD, learning disabilities, auditory processing disorders, or simply those who are distracted by loud noises. When using a behavior-based approach to limit disclosure, it is imperative that the autistic collaborator is in control of their public description.

Provide Accommodations

Reasonable accommodations are changes in the learning environment that afford students with disabilities equal educational access without decreasing program or academic standards (Evans et al., 2017). Accommodations are predictors of academic success for autistic students and should be individualized to fit each student's functional needs within the learning context (Van Hees et al., 2015). Dena notes how absence of accommodations limits participation.

Disability and disability needs are not a competition, nor should these needs be used as gatekeeping tools to deny disabled persons. Not meaningfully understanding the dire nature of what may appear to be a minor accommodation can result in demeaning attitudes and anxiety for the student. Whether one requires relatively small supports or comparatively large ones, the issue remains the same. Without either, one cannot succeed to the best of their capabilities. For example, when taking my comprehensive exams, my accommodations were not in place. The jarring experience of arriving, emotionally charged, facing an all-or-nothing situation and then having to scramble to find separate testing in a building with air conditioning in July, and then having to get a loaner laptop cost me considerable time (navigating to a new building and emotionally regrouping in the bathroom). The second day, with all accommodations in place, I not only completed the task comfortably but within the standard time.

Thus, disability and student affairs professionals should provide accommodations to ensure that autistic students can fully participate in program development and assessment design.

Create Accessible Data Collection Methods and Instruments

Designing data collection methods and instruments that are accessible to autistic participants is imperative for autistic-centered program development and assessment design. Dena explains, "It isn't only how the question is phrased but also the means by which the communication is exchanged. Some autistics may experience expressive language, processing speed, or speech initiation challenges that can result in shut down during assessment protocols." Providing assessment questions in advance or using asynchronous forms of data collection, such as email interviews, discussion threads, or the ability to save responses and return at a later time, are communication techniques that can lessen the burden associated with assessment (Ison, 2009). Dena adds that different ways of asking (matching with a word bank, multiple choice or binary true/false responses) may create a less burdensome effort to participate. Another helpful strategy is to pilot-test the data collection instruments to identify and revise questions that are confusing or do not capture the experiences of autistic students (Brown & Broido, in press).

Develop Organizational Structures for Autistic-Feedback

Engagement of community stakeholders within program development and assessment design does not typically occur during the planning process, rather collaboration tends to occur during program implementation or dissemination of assessment results (Pellicano et al., 2014). However, autistic perspectives are imperative during all phases. Dena expounds:

Students with diverse disability needs must have a safe, proactive, and responsive space to disclose challenges that remain unmet and to foster creative opportunities for activities that help to ex-

pand campus awareness and individual leadership development. This is not optional—it is an essential component of effective program design and assessment.

Thus, professionals should develop organizational structures that foster the "space" for autistic-feedback. Forming autistic advisory boards and partnering with self-advocacy communities are a few prime avenues to collect autistic perspectives and input.

Allocate Time and Resources to Teach Assessment Techniques

Asking autistic students and community members to engage in CBPR needs to be mutually beneficial. In addition to engaging in opportunities to provide autistic expertise, the acquisition of transferable skills are one potential benefit that autistic students can gain from collaborating in the program development and assessment design process.

Disability and student affairs professionals should ask autistic students what program planning and assessment related skills they would like to learn (e.g., library search skills), allocate time to teach or support autistic students as they learn the new skill set, and offer clear and concrete instruction to support autistic individuals in the learning process (Burgstahler & Russo-Gleicher, 2015). Graduate programs that prepare student and academic affairs professionals should consider including these kinds of autistic-centered approaches to program development and assessment in their curriculum. Put another way, we encourage graduate programs to consider teaching individuals in the higher education field about CBPR strategies.

Communicate Program Assessment Findings

When communicating assessment findings, professionals should acknowledge and give credit to autistic collaborators (unless they prefer to remain confidential). Having autistic students communicate assessment findings to stakeholders provides participants with the benefits of presenting their work in professional settings. Dena reflects:

> When the research queries are completed and/or once the research is finalized, it demonstrates value and meaning to utilize the same accessible means to communicate back to the contributors what your findings are and more importantly, how these will foster *change* in how things are done on campus.

Program development and assessment findings should be communicated back to students in an effort to be transparent about the results and to be inclusive of individuals who want to take part in discussions about how to move forward. Findings should also be communicated as internal reports to key stakeholders on campus, such as admissions and retention program offices, to inform institutional practices and policies.

Conclusion

The 10 strategies described above do not fit neatly into program design workshops or assessment textbooks. Unlike typical assessment texts that begin with the identification of educational values, understanding organizational performance, and clearly stating goals (e.g., Schuh et al., 2016), many of the strategies in the autistic-centered model focus on human dignity. It is possible that the themes of inclusion and self-direction may seem simplistic to neurotypical readers; however, experiences of autistic individuals indicate that paternalism is pervasive (Hens et al., 2019).

References

Association on Higher Education and Disability. (n.d.). *Program standards and performance indicators.* Retrieved from https://www.ahead.org/professional-resources/information-services-portal/data-collection-and-management/performance-indicators

Brown, K. R., & Broido, E. M. (2020). Ableism and assessment: Including students with disabilities. In H. R. Ro & E. M. Broido (Eds.), *Voices from the margins: Conducting inclusive assessment for minoritized students in higher education.* (New Directions for Student Services), 31-41. Jossey-Bass.

Burgstahler, S. E., & Russo-Gleicher, R. J. (2015). Applying universal design to address the needs of postsecondary students on the autism spectrum. *Journal of Postsecondary Education and Disability 28*(2), 199-212.

Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment.* University of California Press.

Davis, N. A. (2005). Invisible disability. *Ethics, 116*(1), 153-213.

Dolmage, J. T. (2017). *Academic ableism: Disability and higher education.* University of Michigan Press.

Ewell, P. T. (2009). *Assessment, accountability, and improvement: Revisiting the tension.* National Institute for Learning Outcomes Assessment. Retrieved from http://www.learningoutcomeassessment.org/documents/PeterEwell_005.pdf

Evans, N. J., Broido, E. M., Brown, K., & Wilke, A. (2017). *Disability in higher education: A social justice approach.* Jossey-Bass.

Foucault, M. (1990). *Politics, philosophy, culture: Interviews and other writings, 1977-1984.* Routledge.

Gassner, D. L. (2020). The launching. In R. Bédard, & L. Hecker (Eds.), *A spectrum of solutions for clients with autism: Treatment for adolescents and adults,* 347-353. Routledge Press.

Gillespie-Lynch, K., Kapp, S., Brooks, J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology, 8*, 1-14.

Hens, K. Robeyns, I., & Schaubroeck, K. (2019). Ethics of autism. *Philosophy Compass, 14*, 1-11.

Ison, N. L. (2009). Having their say: Email interviews for research data collection with people who have verbal communication impairment. *International Journal of Social Research Methodology. 12*(2), 161-172.

Lombardi, A., Gelbar, N., Dukes, L. L., III, Kowitt, J., Wei, Y., Madaus, J.,…Faggella-Luby, M. (2018). Higher education and disability: A systematic review of assessment instruments designed for students, faculty, and staff. *Journal of Diversity in Higher Education, 11*(1), 34–50.

Mayhew, M. J., Rockenbach, A. B., Bowman, N. A., Seifert, T. A., & Wolniak, G. C. (2016). *How college affects students: 21st century evidence that higher education works* (Vol. 3). Jossey-Bass.

Miller, R. A. (2015). "Sometimes you feel invisible": Performing queer/disabled in the university classroom. *The Educational Forum, 79*(4), 377-393.

Patton, L., Harper, S., & Harris, J. (2015). Using critical race theory to (re)interpret widely studied topics related to students in US higher education. In A. M. Martínez-Alemán, B. Pusser, & E. M. Bensimon, (Eds.), *Critical approaches to the study of higher education* (pp. 193-219). Johns Hopkins University.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18*(7), 756-770.

Peña, E., Stapleton, L., Brown, K., Stygles K., Broido, E., & Rankin, S. (2018). A universal research design for student affairs scholars and practitioners. *College Student Affairs Journal, 36*(2), 1-14.

Powers, L.E. (2017). Contributing meaning to research in developmental disabilities: Integrating participatory action and methodological rigor. *Research and Practice for Persons with Severe Disabilities, 42*(1), 42-52.

Prince-Hughes, D. (Ed.). (2002). *Aquamarine blue 5: Personal stories of college students with autism.* Ohio University Press.

Robertson, S. M., & Ne'eman, A. D. (2008). Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly, 28*(4), 14-26.

Sarrett, J. C. (2018). Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders, 48*(3), 679-693.

Schuh, J. H., Biddix, J. P., Dean, L. A., & Kinzie, J. (2016). *Assessment in student affairs* (2nd ed.). Jossey-Bass.

Silberman, S. (2015.) NeuroTribes: *A legacy of autism and the future of neurodiversity.* Penguin Random House.

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders, 45*, 1673-1688.

Wall, A., Hursh, D., & Rodgers III, J. (2014). Assessment for whom: Repositioning higher education assessment as an ethical and value-focused social practice. *Research & Practice in Assessment, 9,* 5-17.

Wilke, A., Evans, N., Varland, C., Brown, K., & Broido, E. M. (2019). Access and integration: Perspectives of disabled students living on campus. *Journal of College and University Student Housing, 46*(1), 46-61.

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Table 1

Ten Strategies for Autistic-Centered Program Development and Assessment

Technique	Example
Employ a Community-Based, Participatory Action approach by including autistic students, staff, faculty, or community members as key decision makers.	Engage autistic alumni when developing career services programing (e.g., mock interviews) and designing program assessment.
Develop mutually supportive, trusting, and respectful relationships with autistic people.	Initiate communication, presume competence, and check assumptions or stereotypes.
Use principals of neurodiversity to value and respect autistic differences and expertise.	Foster autistic identity and culture by developing programing that honors autistic pride via media, books, and guest speakers.
Center the goals of the autistic students and community members by soliciting input before program development or assessment.	If requested by autistic collaborators, include metrics for sensory stimuli (e.g., microphone noise) in assessment of social programing.
Protect confidentiality or privacy when desired and ensuring autistic collaborators have control over their disclosure narratives.	Limit public disclosure by offering the option to say, "student has trouble focusing in a busy room" instead of "the student is autistic."
Provide accommodations so that autistic students can fully participate in program development and assessment design.	Communicate the process for requesting accommodations and work with Disability Resource professionals to ensure provision.
Create accessible data collection methods and instruments.	Provide questions in advance or use asynchronous forms of data collection.
Develop organizational structures that foster a dedicated "space" for autistic-feedback.	Build and utilize autistic advisory boards.
Teach assessment techniques.	Allocate time and resources to teach data analysis so that autistic participants gain transferable skills
Communicate program assessment findings and give credit to autistic collaborators (unless they prefer to remain confidential).	Support for autistic collaborators if they wish to present assessment findings to stakeholders.