

# Advancing Mental Health Supports for Autistic Postsecondary Students: A Call for Research

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## Abstract

Research has documented elevated rates of co-occurring depression and anxiety in autistic adults, with some noting particularly high rates for autistic students enrolled in postsecondary education (PSE). Difficulty coping with the stressors that accompany daily life as they navigate college campuses may contribute to development or exacerbation of co-occurring conditions. Autistic students have reported that depression, anxiety, and stress interfere with their success in college, but that they have difficulty identifying and accessing the supports that they need. Though many postsecondary institutions have established programs that provide academic supports to autistic students, few programs directly support mental health and wellness. Recently, stakeholders have advocated for mental health to be prioritized in adult autism research. We suggest that a specific focus on autistic students in PSE is warranted and provide a brief overview of the relatively limited literature in this area. To inform development of mental health services and supports that will be both accessible and acceptable to the range of autistic students attending PSE, research is recommended in four areas: factors positively and negatively affecting mental health, types of supports, outreach, and on-campus training and education. It will be essential for researchers to establish community partnerships with autistic individuals to inform study design and specific research questions. This will ensure that autistic voices guide development of supports that will foster positive mental health in PSE and beyond.

**Keywords:** autism, mental health, young adult, postsecondary education

## Lay Summary

*Why is this topic important?*

Autistic adults experience high levels of anxiety and depression. In addition, autistic individuals and their parents want mental health to be prioritized in research. Attending postsecondary education, such as at a 2-year college or 4-year university, presents autistic adults with unique challenges that may contribute to additional mental health concerns. While many postsecondary institutions offer academic and social supports, it is unclear how equipped they are to provide adequate mental health supports. Thus, it is important to understand what programs and services are needed, and wanted, to best support the wellness of autistic students.

*What is the purpose of this article?*

This article highlights the need for more research to focus on the mental health of postsecondary autistic students. While some researchers have focused on the mental health needs of autistic adults and college students separately, it is important to understand the experiences of autistic students and what supports they might want and benefit from.

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*What are the perspectives of the authors?*

The first author of this perspective article is a doctoral student with 3 years of clinical research experience with autistic adults. The second author is an international speaker, autism sexuality advocate, consultant, and autistic adult. The third author is a clinical psychologist and researcher with over 15 years of experience working with autistic individuals across the lifespan.

*What is already known about this topic?*

Researchers know that autistic individuals, including those enrolled in postsecondary education, experience higher rates of co-occurring conditions when compared with their neurotypical peers. We also know that while many colleges and universities support autistic students in a few areas (e.g., academics, social), most do not offer mental health supports in their autism programs. There is some evidence to suggest that campus counseling centers and mental health providers in the broader community often lack knowledge and understanding of autism that is important to providing appropriate mental health supports for autistic students.

*What do the authors recommend?*

We recommend that research focus on four areas: factors positively and negatively affecting mental health, types of supports, outreach, and training and education.

Specific research is needed to further explore the relationship between socialization and both negative (e.g., loneliness) and positive mental health (e.g., life satisfaction).

Research in these domains should include diverse samples, prioritize collaborating with autistic adults at all stages of study design and implementation, and be conducted at different types of postsecondary institutions (e.g., 2-year colleges; larger universities) and instructional settings (e.g., virtual, small classrooms) around the world. These study features are critical to ensure that the research questions being asked would make contributions to the field that are meaningful to autistic students.

In addition, the authors suggest that postsecondary institutions promote neurodiversity and inclusion to enhance the acceptance of autistic students by peers, faculty, and staff.

*How will these recommendations help autistic adults now or in the future?*

These recommendations may help to inform future research and supports that will promote autistic postsecondary students' overall wellness during their educational experiences.

**Introduction**

RESEARCH HAS DOCUMENTED high rates of anxiety, depression, and suicidality in autistic adults.<sup>1–3</sup> For autistic people, prevalence of depression and anxiety has been estimated at 23%–27%,<sup>1</sup> much higher than 1%–12% estimated in the general population<sup>4</sup> and 2%–25% of clinically referred neurotypical adults.<sup>5</sup> Autistic adults and other stakeholders have labeled mental health as a priority area for future autism research.<sup>6</sup> While research aimed at understanding mental health in the broader population of autistic adults is increasing, few studies have focused on the emotional well-being of those in postsecondary education (PSE).

Using data from the National Longitudinal Transition Study-2, Shattuck et al.<sup>7</sup> reported that 34.7% of individuals with a high school special education classification of “Autism Spectrum Disorder” in the United States attended a 2- or 4-year college within 6 years of completing high school. More recent work has estimated that 41%–58% of autistic high school students in the United States attend PSE.<sup>8</sup> Data from a large public university in the southeastern United States suggest that 0.7%–1.9% of university students may meet criteria for autism.<sup>9</sup> These numbers likely underestimate the proportion of autistic individuals

enrolled in PSE, as some autistic individuals do not receive special education services<sup>10</sup> and others may be diagnosed later in adulthood.<sup>11</sup> There has been some suggestion that college graduation rates may be lower for autistic adults,<sup>12</sup> which limits long-term job prospects and maintains financial reliance on government supports.<sup>9</sup>

Several small studies have suggested that autistic college students report experiences of depression, anxiety, social isolation, and marginalization during their college years.<sup>13,14</sup> In a recent survey of fourteen 2- and 4-year colleges, autistic students ( $n=89$ ) were more likely to self-report elevated symptoms of depression and anxiety and diagnoses of co-occurring conditions than their neurotypical peers.<sup>15</sup> Mental health services may be essential to not only promote wellness during the transition to PSE, but also successful completion of degrees.<sup>11,16</sup> Research fostering better understanding of the specific needs of postsecondary autistic students is emerging; however, more attention to their mental health is needed to inform development of supports to promote well-being and successful educational outcomes. The focus of this article is to briefly summarize the current state of the field and suggest future directions for research and clinical practice. The goals outlined reflect the perspectives of the authors, who work with autistic postsecondary students in clinical and research practices, as well as the personal lived experience of one coauthor.

## Mental Health in PSE

In the general population of college students, there is an increase in both mental health needs and demand for services.<sup>17</sup> The transition to college is particularly difficult for many students due to the increased social, emotional, and organizational demands of emerging adulthood and PSE. Self-determination and self-regulation are hypothesized to serve as critical skills for a successful adjustment to PSE.<sup>18</sup> Navigating PSE is especially stressful for autistic students who need supports in these areas.<sup>9,19</sup> Without adequate supports, the transition may be marked by prolonged distress, thereby exacerbating their already elevated risk for co-occurring mental health conditions. The first semester in a postsecondary environment presents challenges as students navigate multiple novel complex social demands, such as interactions with professors and peers in dorms.<sup>20</sup> Autistic college students have reported feeling misunderstood by faculty and staff, who often do not create inclusive environments for students' individual needs.<sup>21</sup> Autistic college students also report wanting to be treated equally to others and to form genuine connections, regardless of their decision to disclose their diagnosis.<sup>22</sup> In addition, students need to adjust to a more student-directed learning environment<sup>23</sup> (i.e., including nonscheduled projects or laboratories that students are expected to integrate "on their own time") and more frequent changes in routine, as each day on a college campus and each class they enroll in may be structured differently. This is a stark contrast to the teacher-guided learning and more predictable consistent routines experienced in high school. Changes in environmental demands are particularly heightened for students who live independently on- or off-campus, given the stressors that accompany living away from parents for the first time<sup>20</sup> or possibly having a stranger for a roommate. Sensory responses (e.g., to crowded areas or classroom lighting) may also cause distress or lead to social isolation that may contribute to anxiety and depression.<sup>24</sup> Seeking out services and advocating on their own behalf may further overwhelm some, and there may be an emotional toll of having to be labeled as "disabled" to receive supports. Stress experienced during this transition may contribute to the development or exacerbation of depression and anxiety in this population<sup>25</sup> and may heighten the risk for suicide.<sup>20</sup>

Of course, mental health concerns extend beyond the 1st-year transition, as transitions are constantly present throughout the postsecondary experience. Difficulties regulating negative emotions and reliance on maladaptive regulatory strategies may make it difficult for autistic adults to adapt to situational demands,<sup>26</sup> contributing to the challenge of adapting to a barrage of stressors and transitions. Within a single day, classes are held in different buildings and led by different instructors. Week-to-week changes may occur in class structure (e.g., lectures vs. discussion), location (e.g., examinations being delivered in testing centers), and other schedules (e.g., buses operating at different frequencies throughout a term). Each term, schedules change, while each year may be marked by moving to a different dorm or shifting to off-campus housing. As students transition out of PSE, added stressors are introduced, such as searching for employment or loss of eligibility for student or parent health insurance. Beyond transitions, autistic students are at risk for bullying and sexual abuse.<sup>15,27</sup> Autistic females also experience higher rates of unwanted sex-

ual advances.<sup>28</sup> Considering these persistent challenges, it is perhaps unsurprising autistic students report significantly lower quality of life than nonautistic peers<sup>29</sup> and have cited co-occurring conditions such as anxiety and depression as one of their top five barriers to college success.<sup>16,21</sup> Following trends in nonautistic populations, autistic female students may be at even higher risk for these mental health issues than male students.<sup>30</sup> Parents and other stakeholders also identify self-advocacy and emotion management as areas that autistic students need the most support throughout their PSE.<sup>19,31</sup> Of particular concern are the rates of suicidal ideation and behaviors that may be present in autistic adults in PSE, with one study finding that 53.6% of students thought about suicide in the past year, and that 40% of students contemplated a suicide plan during their lifetime.<sup>14</sup> While specific reasons for these elevated rates need to be explored, experiences of marginalization and social isolation are commonly reported by postsecondary autistic students.<sup>13</sup> For some individuals, persistent feelings that they must camouflage, or mask, certain behaviors may contribute to psychological distress and suicide risk.<sup>32</sup> While research often seeks to understand risk for negative outcomes, more research on positive psychology and factors promoting well-being are clearly needed. Emerging research demonstrates that perceived acceptance by peers is linked to positive mental health in autistic adults,<sup>33</sup> and higher levels of social connectedness are related to greater life satisfaction in both autistic and neurotypical college students.<sup>34</sup>

## Supports for Autistic Postsecondary Students

Academic supports have been identified as the most widely offered and utilized by autistic postsecondary students.<sup>35</sup> These programs often aim to promote academic success by offering supports that target executive functioning skills, such as working with other students on time management needed to complete assignments and extended time on examinations and assignments.<sup>36</sup> Considering that executive function skills play a large role in learning to successfully balance multiple aspects of college life<sup>37</sup> and several studies have suggested that many autistic adolescents and adults exhibit difficulties in executive functioning,<sup>38</sup> such programs likely provide valuable support. While autistic college students report the importance of executive functioning skills for success in PSE,<sup>21</sup> the extant literature, including stakeholder perspectives, indicates a clear need for both academic and nonacademic supports to promote their postsecondary success.<sup>13</sup>

Parents of autistic students in PSE have reported that current services often do not sufficiently capture nonacademic needs, such as socialization and mental health.<sup>39</sup> Some on-campus programs have aimed to address these gaps by offering social supports (peer mentors, assistance organizing extracurricular events, etc.).<sup>36</sup> Increasing autistic students' access to social opportunities may impact their overall satisfaction with college and their academic success.<sup>40</sup> This may also be a first step toward reducing marginalization and social isolation. There is also emerging evidence that transition programs such as *The Stepped Transition in Education Program for Students with ASD (STEPS)*<sup>41</sup> targeting adjustment to college may have mental health benefits in addition to promoting successful

adaptation to PSE.<sup>42</sup> The STEPS program supports autistic adults as they transition from high school into PSE, and equips participants with self-determination and self-regulation skills necessary for young adulthood.<sup>43</sup> There are few programs, however, designed to directly address mental health needs.

While on-campus counseling centers are available to provide students with mental health support, there has been a spike in demand over recent years, particularly for students seeking support for generalized anxiety, depression, and social anxiety.<sup>17</sup> It is not clear to what extent counseling centers are equipped to support autistic students. Some autistic college students report that counselors often do not have appropriate understandings of autism.<sup>44</sup> There is also data to suggest that autistic students may need more sessions to accomplish their goals and be more likely to return to treatment throughout college than nonautistic students, despite presenting with similar levels of distress at intake.<sup>45</sup> While reasons for persistence and recurrence of symptoms remain to be explored, this suggests that autistic students may benefit from longer term care than is typically provided in on-campus counseling centers. Unfortunately, however, outside of universities, community mental health providers also report feeling unprepared to work with autistic adults, due to limited knowledge and experience.<sup>46</sup> A lack of providers likely contributes to the experiences of autistic young adults who indicate that they would like to receive therapy during their postsecondary years, but face barriers such as cost and long waitlists.<sup>25</sup>

### Recommendations for Future Research

To advance mental health supports in a meaningful way for autistic students, we suggest a need for more systematic investigation in four areas: (1) factors positively and negatively affecting mental health, (2) type of supports, (3) outreach, and (4) on-campus training and education. Across these areas, research must be conducted in recognition of the increasing mental health needs and service demands already being observed on college campuses<sup>17</sup> and, wherever possible, seek to identify overlapping and unique experiences of autistic individuals to inform integrated approaches that will foster accessibility for both students who are engaged in other campus supports and those who do not want their diagnosis disclosed by affiliating with an autism-specific program. We acknowledge that much of the research on autistic experiences in PSE is limited to predominantly White, U.S.-based samples. Future research must include a diverse range of backgrounds, allowing investigation of intersectional identities. Cultural differences and differences in educational systems also warrant research in other countries. In addition, community-based partnerships with autistic adults collaboratively designing and implementing studies are essential. Partnerships will aid in reducing the traditional imbalance of power in research, and promote the perspectives of autistic individuals beyond survey responses.<sup>47</sup> This will help to ensure that research reflects the priorities of autistic students and will inform development of supports needed and desired by the population for which they are intended.

First, more systematic investigation is needed to identify the factors positively and negatively affecting mental health of autistic students in PSE, and to what extent these factors

are similar to the general population of college students or unique to those on the autism spectrum. More specifically, understanding how transitions (e.g., beginning PSE, new terms) and on-campus experiences (e.g., involvement in clubs, interactions with other students) affect mental health may offer insights into intervention targets and supports. While several qualitative studies have explored this in small samples and one recent multiuniversity study,<sup>15</sup> there is a need for more larger scale studies that include diverse postsecondary settings and participants.<sup>13,48</sup> Recent large-scale research efforts that have addressed mental health needs of postsecondary students in the United States<sup>17</sup> and internationally<sup>49</sup> have not explored needs of autistic students or other special populations. To promote inclusivity and understand the needs of neurodiverse students, study recruitment should be campus wide, including both students who receive disability services and those who chose not to disclose their diagnosis to the university.

In addition, it will be important to consider whether there are discrepant needs of students enrolled in different types of PSE (e.g., community college, 4-year university, graduate school) and different programs within these settings. For example, autistic students attending 2-year colleges reported a higher sense of belonging than both neurotypical peers and autistic students attending 4-year institutions, which may be due to differences in social demands.<sup>15</sup> This might also reflect topographical differences in these types of institutions (e.g., class size, program features). In the general population, PSE students attending medium or large institutions were more likely to report anxiety than those at small schools.<sup>50</sup> Research has suggested that autistic students in STEM programs were twice as likely to transfer from 2-year community colleges to 4-year universities than students in other fields.<sup>51</sup> Moreover, the coronavirus disease 2019 pandemic has highlighted a gap in our understanding of the potential benefits or drawbacks of online learning models for autistic students. While virtual classrooms may limit some challenges (e.g., navigating campus, sensory experiences in lecture halls), they may also make it even more difficult to establish relationships and promote feelings of social isolation.

Research is also needed to identify social opportunities or supports that reduce negative psychological effects (e.g., loneliness) and increase life satisfaction and well-being of autistic students. While many institutions offer peer mentorship programs, research has yet to evaluate whether these programs are socially rewarding or beneficial to participants. Some students may find an assigned social contact to be demeaning or disingenuous, possibly offsetting potential positive effects of social opportunities or genuine acceptance by the peer. Understanding “naturalistic” methods of socialization may also provide insight into larger scale approaches to promoting positive mental health. For example, exploring whether fields of study that tend to offer smaller classes or small-group opportunities foster relationships and acceptance, or whether residential programs that offer smaller “cohorts” of students to connect with within larger universities provides environments more conducive to socialization. These future studies should also include careful consideration of the relationship between perceived versus received support and acceptance and how these influence positive mental health. More broadly, understanding the association between psychological distress (i.e., anxiety and

depression) and positive psychological attributes, such as life satisfaction and happiness, is needed to avoid overemphasis on responsive treatments and ensure development of supports that aim to promote overall well-being.

While large-scale survey studies, such as that done by McLeod et al.,<sup>15</sup> offer important insights, there is also a need for qualitative studies to answer important questions regarding the extent to which existing mental health supports address their needs and what kinds of specialty supports may be desired. Understanding the factors affecting mental health will inform evaluation of existing on-campus supports and be critical to fostering development of proactive approaches to promote positive mental health, reduce distress, and prevent crises. This may include regular monitoring and communication support throughout postsecondary years and programs to encourage self-advocacy for mental health and other needs.<sup>19,41</sup> Another possibility might be campus-wide initiatives offered to promote wellness, such as mindfulness-based stress reduction programs.<sup>52</sup> Programs to foster development of life skills (e.g., laundry) or guidance on navigating specific campus areas (e.g., the cafeteria, shared bathroom spaces) may have both direct (reducing stress) and indirect (promoting positive social interactions) effects on autistic students' mental health. Specific topics, timing (e.g., for the entire term vs. during high-stress periods, such as midterm or finals week), and format (e.g., individual, group, through videoconference) preferences could be investigated in survey studies and explored in-depth through additional qualitative interviews or focus groups with autistic adults and other stakeholders at different institutions.

As services are developed, special attention to outreach efforts will be important. Autistic students report many barriers to accessing mental health services, ranging from their own anxiety and depression interfering with their ability to seek out support<sup>53</sup> to navigating complex service systems, costs, and waitlists.<sup>25</sup> Thus, developing and assessing different ways to facilitate access, without requiring student initiation, will be an important component of program development, as some students may struggle to advocate for what they need. In addition, knowing that many autistic individuals may not consider themselves to have a disability, and thus may not self-identify and seek services from disability offices<sup>10</sup> reminds us that we must ensure these efforts are broadly disseminated across campus in a manner that does not require diagnostic disclosure. Stigma has long been acknowledged as a barrier to students accessing mental health care.<sup>54</sup> Multifaceted models to support mental health, including substance abuse and suicide prevention efforts, that have been developed for college campuses with these challenges in mind<sup>55</sup> may be useful to inform autistic supports.

As we advance research efforts, it will be important to consider training and implementation practices and incorporate systematic investigation to improve rapid dissemination. Considering research suggesting limited confidence and competencies of general practitioners in working with autistic adults,<sup>46</sup> it is important to work with existing providers to identify service gaps and develop and validate methods for provider training and implementation. One advantage of on-campus research is the potential for programs to incorporate graduate student training into service delivery, thereby simultaneously increasing the number of community providers

with these competencies. Models that embed competencies in university counseling centers may mitigate need for "specialty" care and be more inclusive of neurodiverse students with different needs.

Finally, attention must be paid to the need for more systemic changes on-campus, both to reduce experiences of victimization and marginalization and to create a more inclusive and accommodating postsecondary setting. While there is a tendency to emphasize person-focused interventions to ameliorate or prevent mental health challenges, fostering understanding of autism and appreciation for neurodiversity on college campuses may be an important facet of systemic intervention that can go a long way to promote more positive mental health for autistic students. For instance, colleges and universities may consider inviting autistic advocates to speak at campus-wide events and share their experiences in order for the student body to increase their awareness of neurodiverse preferences and challenges. Ideally these events could happen as part of wider campus diversity efforts, rather than only during autism-specific events (e.g., Autism Awareness month). Information and training opportunities to increase understanding of autism should be made available to students, faculty, and staff. These efforts are hoped to reduce pressures to camouflage and the burden of explaining autism that often falls on autistic students. Understanding and support from instructors might facilitate requests for accommodations, particularly in the absence of disclosure to a disability services office. Increased knowledge may also encourage greater acceptance of differences and recognition of autistic strengths.

## Conclusion

Mental health has been highlighted as a priority area for autism research.<sup>6</sup> Previous researchers<sup>31</sup> have highlighted a need for research aimed at supporting autistic students in PSE. In this perspective article, we emphasize a need for future research to focus on the mental health needs of this group. Understanding of the specific factors both promoting positive well-being (i.e., happiness, life satisfaction) and those increasing risk for depression, anxiety, and psychological distress is needed to inform development of programs. Rapid dissemination will be fostered by inclusion of autistic students and other stakeholders to inform services, training, and outreach models that are both acceptable to the autistic students and feasible in different postsecondary settings.

## Authorship Confirmation Statement

The authors confirm contribution to the article as follows: G.B.G. and V.H.B. were involved in the original conception of this perspective article, A.G. broadened the conceptualization to include more nuanced perspectives of autistic people, and all authors critically revised the article for intellectual content and approved the final version of the article. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

## Author Disclosure Statement

V.H.B. is the director of the Rutgers Center for Adult Autism Services Psychological Services Clinic (RCAAS PSC), a small clinic that provides psychological services to

autistic adults at Rutgers and the surrounding community. This includes both fee-based and free services that are offered through research programs. A.G. is a consultant and public speaker on topics related to autistic adults. No competing financial interests exist for G.B.G.

### Funding Information

This research was supported by K23MH115166-01 to V.H.B.

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