

# Benchmarks to Inclusion: Creating Core Principles to Facilitate Autistic Student Success in Higher Education

## Background

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As recognition and diagnosis of autism continues to increase, more and more autistic people are entering higher education institutions across the United States. According to the National Autism Indicators Report, it is estimated that 36% of autistic young adults attend college (Roux, Shattuck, Rast, Rava, & Anderson, 2015). Although more autistic individuals have gained access to higher education, they have lower completion rates than other students: only 38.8 percent of autistic students obtain a degree, in comparison to 40.7 percent of disabled students overall, and 52.4 percent of the general population of students (Jackson, Hart, and Volkmar, 2018).

In order to address this disparity, many colleges and universities have created support programs specifically for autistic students. College Autism Network documents that there are over 60 of such programs within the U.S. (2019). However, these programs vary widely in terms of what kinds of support are provided to students, as well as how success is measured for students within these programs. There are currently no universal standards for autism support programs to follow in order to ensure autistic student success.

This is indicative of a larger program within higher education institutions: campuses lack understanding of what barriers autistic students face when trying to achieve success, and how campus administration can address these barriers. There is relatively little literature that focuses specifically on autistic student's experiences in higher education; the majority of research that does exist on students with disabilities in general primarily centers students with learning disabilities, and to a lesser extent, students with psychiatric or physical disabilities. Compounding this issue, much of the literature on autism and higher education consists of case studies, which offer little information that is generalizable to positively impact student success across different colleges and universities (Gelbar, Smith, and Reichow, 2014).

The framework of autism research also stymies efforts to create systemic change at institutions of higher education. Research about autism is generally led by non-autistic researchers, who oftentimes fail to incorporate a civil rights framework into their research, instead analyzing autistic individuals and their behavior with a pathologizing lens (Milton, 2014). In the literature on autism and higher education, challenges that autistic students experience are oftentimes portrayed as individual problems rather than institutional barriers, contributing to the stigma that autistic students face and shifting the onus of supporting autistic students away from their colleges and universities. There remains a dearth of research that centers the voices of autistic students and provides perspectives on how to improve their campus environments (Gelbar et al, 2014).

In addition, few studies have considered how being a part of multiple marginalized groups, such as autistic students who are low-income, students of color, or LGBTQ, could impact the experiences of these students.

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*The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!*

This may be due in part by the medicalized nature of autism research leaving autistic students out of the conversation concerning broader civil rights efforts, but also reflects broader attitudes within disability studies research that often fail to include the perspectives of multiply marginalized communities, especially when it comes to disability and race (Ferri, 2010). Adopting research initiatives that focus on achieving equity for autistic students necessitates amplifying the voices of autistic students whose marginalization extends beyond solely being autistic.

Furthermore, there are multiple definitions in use within the literature about what constitutes “success” for autistic college students. Many studies focus solely on retention and graduation rates as a barometer of success, usually referred to as “persistence” through college (Venezia, Callan, Finney, Kirst, and Usdan 2005). Academic achievement is also often used to gauge whether or not a student is successful (Fleming, Oertle, Plotner, and Hakun, 2017). However, these measures may not take into account how autistic students themselves view their own success. For example, an autistic student may feel unsuccessful if they do not feel prepared for employment post-graduation, even if they completed college with an excellent GPA. Other autistic students may regard getting good grades as less imperative to their successful college experience than having an active social life. The disconnect between what institutions view as success in comparison to how autistic students think could lead to the needs of autistic students going unaddressed (Wilke, Varland, Brown, Broido, and Evans, 2019).

Regardless of the definition of success, numerous studies have identified a variety of factors that influence the success of autistic students. One paper claims that having a sense of “belonging” on campus is a key contributor to success (Leake & Stodden 2014). Another reports that students with more self-determination skills tend to be more successful (Jameson, 2007). Having a sense of “purpose” is also noted to positively correlate with higher education success (Belch, 2005). However, similar to the pitfalls of literature illustrating challenges autistic people face, these studies usually focus on characteristics of individual successful autistic students, rather than the characteristics of institutions of higher education that foster success in their autistic student population.

Preliminary measures have been created which outlines the traits of colleges and universities that bolster the success of disabled students, and/or provide rough guidelines for institutions of higher education to follow in order to facilitate success. The Association on Higher Education And Disability (AHEAD) produced a Professional Standards and Performance Indicators document to instruct Offices for Students with Disabilities (OSD) on how to best accommodate disabled students. However, these standards place a large influence on compliance with the Americans with Disabilities Act (ADA) and meeting the minimum standards of the law, even though it is documented that the range of accommodations that OSDs offer is not sufficient to facilitate student success (Longtin 2014).

In 2008, the Higher Education Opportunity Act (HEOA) was passed, which enabled students with intellectual disabilities to access certain types of financial aid to participate in campus-based comprehensive transition programs (Lee, 2009). The HEOA also allocated funding to model demonstration programs known as Transition and Postsecondary Programs for Students with Intellectual Disability (TPSIDs). While TPSIDs do not serve autistic students specifically, some autistic people with co-occurring intellectual disability do participate in these programs. ThinkCollege, the organization that oversees TPSID programs, created a list of principles for these programs to follow. These principles identify four pillars to support student success: academic access, career development, campus membership, and self-determination (Grigal, Hart, and Weir, 2012).

In the recently-introduced College Affordability Act, which would reauthorize the HEOA, language is included that builds on the ideas outlined by ThinkCollege. The bill specifies that TPSID programs must integrate students with intellectual disabilities into the general campus environment in all aspects of the campus experience, including housing, work experience, extracurricular activities, and academic courses. It also mandates that TPSIDs work with each student in order to identify their individual goals and create a plan to achieve those goals (College Affordability Act, 2019). While these standards are more comprehensive, they were cre-

ated without input from students with intellectual and developmental disabilities, and may be missing key concepts to help students be more successful.

It is clear that campuses must go above and beyond the law in order to ensure the success of their autistic student population, and it is impossible to identify the priorities that campuses should focus on improving without consulting autistic students themselves. However, before we begin creating a student-centered framework for autistic student success, we must first discern how autistic students define their own success. This paper aims to generate a working definition of “success” as it is defined by autistic students, as well as identify what structural barriers students face when attempting to achieve success in college. We will use this feedback to create a list of core principles that campuses should keep in mind in order to set up their autistic students for a successful higher education experience.

## Methods

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Ten autistic people who had participated in the Autistic Self Advocacy Network’s Autism Campus Inclusion (ACI) Summer Leadership Academy were interviewed either individually or in small focus groups. We chose this sample because participants in ACI showed interest in facilitating the success of disabled students on their campuses, and we felt these students would have unique insight as to how higher education institutions might help autistic students achieve success. In order to account for differing experiences in college, this group consisted of a mix of individuals who had either completed college with a degree, are currently in college, or whom attended college but were unable to complete a degree. We also recruited students with a variety of backgrounds, including students of color, LGBTQ+ students, non-speaking students, and students with co-occurring developmental, psychiatric, and/or physical disabilities, to better understand how belonging to multiple marginalized groups might affect higher education success.

In addition to interviewing students, we conducted six one-on-one interviews with autistic individuals who are experts on the topic of disability in higher education. These individuals included three current PhD candidates whose research focuses on autistic students in college, two employees of non-profit organizations that serve college students with disabilities, and one director of an on-campus autism support program. We chose to consult these individuals to challenge the misconception that autistic people cannot be subject matter experts on topics related to autism, as well as to gain insight on aspects of working within the higher education system that neurotypical faculty, staff, or researchers might miss.

Both the sample of autistic college students and experts were asked about the following subjects:

- How they would define “success” for autistic college students.
- What data they felt campuses should collect to measure the success of autistic college students.
- What structural barriers autistic students face when trying to achieve higher education success.
- How they felt campuses should address these structural barriers/Ways their campuses helped facilitate success for autistic college students.
- Their opinion on autism support programs, as well as their experiences in these programs (if applicable).

## Results

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### **Defining and Measuring “Success”**

All parties agreed that retention/graduation rates, as well as academic achievement, were one aspect of success for autistic college students. However, it was clear that these factors were not considered the most important when conceptualizing success. While previous research identified self-determination as a contributor

to student success, student participants identified self-determination as a form of success in itself when it came to their higher education experiences. Some student definitions included, “learning what I want to learn in the way I am best able to learn it,” as well as “being able to achieve what you want out of college, not what other people think you should want.” One expert went a step further and stated, “Success isn’t about graduation - it’s about discovering what you want to do,” relaying a story of a student they worked with who realized that college was not for them, and was able to get a job they loved after dropping out.

Another salient theme was inclusion as a form of success. Students felt that a key way to measure autistic student success was to compare how similar their college experience was to non-disabled peers; that is, being fully included at their college to the point that their college life looked no different than any other student’s. Responses included defining success as “Being included with everyone else,” “Attending school in the same way as other peers,” and “Being able to access all aspects of my college life.” When asked to describe what a successful college experience would look like for autistic students, one expert claimed that this experience “Would look a lot like an ideal experience for a non-disabled student.” Students also explained that a key indicator of inclusion was a sense of belonging: “Feeling like part of a community” and “To always feel like I’m welcome [on-campus].” were indicated as ways students measured their own success.

Respondents noted that it was crucial to acknowledge that success for autistic students required looking holistically at each facet of campus life. One student clarified that success for them was “not just getting good grades...but being included in on-campus jobs or homecoming or clubs.” Another student added that success involved “learning life skills, and preparing for the next step [post-graduation].” Participants agreed that success was more than just outcomes within college, but also after college. A student identified “having the tools necessary to prepare for the workplace” as another indicator of autistic student success. Experts cited employment as one way they conceptualized success, which they viewed as especially relevant considering the chronic un- and underemployment that autistic adults face (Roux et al, 2015).

Examining employment outcomes was the most straightforward metric interviewees identified that campuses could utilize to measure autistic student success. Participants expressed that they did not feel college adequately prepared them for employment, so measuring post-graduation outcomes could indicate how much effort higher education institutions devote to helping autistic students access employment opportunities. Employment satisfaction was also discussed as a measure, which a student described as “Being meaningfully employed vs. [just] employed,” noting that even if an autistic person was able to obtain employment post-graduation, their job may not be fulfilling or relevant to their field of study. One expert stated the need for more longitudinal studies to “follow student pathways through and beyond college.”

While graduation rates were still considered as an important piece of measuring success, participants added that these measures must consider that autistic students may need to take a reduced course load to accommodate their disability. As a result, if the graduation rate is measured solely on a 4-year or 6-year basis, these numbers may be missing autistic students who do eventually graduate past that timeframe, or place pressure on autistic students unable to meet those deadlines. In addition, one student stated that campuses should consider the percentage of students with disabilities who return to their colleges after taking a leave of absence, as this reflects an alternative way that students might “persist” through college.

Interviewees again detailed the potential dangers of focusing solely on academic achievement as a measure for success. A student said that they felt grades should be “the least important factor” when measuring success. One expert noted that campuses may use the fact that many of their autistic students are succeeding academically as an excuse not to collect additional data about their college experiences.

Instead, the majority of interviewees emphasized student satisfaction as the best way to gauge the success of autistic students. Measuring levels of social engagement and perceived support on-campus were specified as ways to understand a student’s overall happiness and emotional well-being. While they acknowledged that it would be more difficult to capture this information in comparison to other quantitative measures, the idea arose of asking both autistic and neurotypical students about different aspects of campus life as a barometer

for success. For example, students could be asked about how often they participated in extracurricular activities vs their desire to participate in these activities. Participants also detailed certain disability-specific quality measures, such as asking if autistic students felt they were receiving all the accommodations they need to succeed, or if they felt like the overall campus climate was welcoming to disabled students.

## **Barriers to Success**

### *Transition*

One of the largest hurdles to achieving success in college is acclimating to the campus environment. The majority of schools offer little guidance on the myriad of ways that college differs from high school, and expect students to handle this drastic shift in climate on their own. However, these adjustments may not come naturally to autistic students. Focus group participants indicated that they oftentimes felt unprepared as they attempted to adjust to the new academic, social, and independent living expectations that they faced in higher education. Topics such as how to make friends, connect with professors for course assistance, and navigate campus housing were brought up as areas that students needed information about, but had to figure out on their own upon beginning their college career. Many students specifically referenced “navigating academic culture” as something they noticed during their transition as being an important part of achieving their college goals, but lacked the tools to do so successfully.

Students also expressed that there were few resources from their schools that detailed what areas students with disabilities could receive assistance with. Since many autistic people have difficulty with communicating over the phone, students would attempt to find information about disability services through their college websites, which were described as generally vague and/or confusing. This lack of information forced some students to wait until they arrived at their campus to attempt to arrange accommodations for their disabilities. This added another layer to the overwhelming experience of adjusting to the lifestyle changes of college.

While some students went through campus orientation programs provided by their colleges to ease their transition, these orientations were described as being inaccessible to autistic students in a variety of ways. Orientation activities were too loud or crowded for autistic students to participate, information was provided in formats that autistic students could not understand (such as only being provided verbally), or students were forced to participate in “relationship-building” exercises that asked autistic participants to engage in ways that were harmful to them (such as by maintaining eye contact). These orientations very rarely mentioned disability in any way, or provided any information specifically to assist students with disabilities.

### *Accessing and Receiving Accommodations*

As mentioned in regards to transition, many autistic students expressed difficulty accessing information regarding receiving disability accommodations. For many, their first hurdle came when trying to obtain sufficient documentation of their disability status. In some cases, students reached out to their disability services office to ask for information, only to be told that the office could not assist them unless they already had official documentation of their disability. Even students who had prior disability diagnosis occasionally lacked a form of documentation that their disability services office regarded as valid, and were made to obtain additional documentation. Because disability accommodations do not apply retroactively, as students worked to gain access to the help they needed to succeed, they were already facing the consequences of lacking these accommodations, potentially being set up for failure that could not be reversed.

There are a variety of reasons why an autistic student may not have access to the diagnostic services that can provide disability documentation accepted by colleges. Diagnostic services may be too large of a financial burden for low-income students to obtain, or could be inaccessible due to not being provided on-campus. Because of racist and sexist beliefs that autism occurs predominantly in white men, doctors are also less likely to diagnose autistic women or autistic people of color. These barriers meant that students with informal or

self-diagnosed autism oftentimes could not obtain an official autism diagnosis, leaving them unable to access disability accommodations in college entirely.

Some participants described additional difficulties accessing the physical location of their disability services office. Figuring out where the office was located served as the first roadblock, as even this basic information was not well-advertised. Some of these offices were located in inaccessible buildings, or on remote parts of the campus that were unfeasible for students to find and traverse to. In one instance, a student who attended college in a major city was told that their disability services office was located off-campus in a building across town. While this is an extreme case, it magnifies the general issue of students being unable to locate or access these offices. Compounding this is the general lack of staff for these offices, requiring students to potentially wait weeks for an appointment to receive accommodations.

Students who were able to overcome these obstacles and secure a meeting with their disability services office faced further trials regarding what accommodations they were entitled to receive. One student recalls that they were required to write “A 500-word essay about why [they] needed accommodations” in order to be granted any assistance. Others recounted being met with confusion or derision when requesting accommodations for multiple disabilities, as disability services offices felt unequipped to deal with multiple access needs. For example, a student who identifies as autistic and has visual impairments was given accommodations for autism, but refused accommodations for their vision impairment. Furthermore, students recalled being given a list of potential accommodations and being requested to choose what they needed from this list, limiting the kinds of accommodations they could ask for. One expert challenged that the approach of providing a “laundry list” of accommodations can leave students who would benefit from non-traditional accommodations with unmet needs.

Once a student was able to get accommodations in place, making sure these accommodations were properly implemented served as an additional challenge. Participants spoke of professors who refused to accommodate their disabilities, or whose ableist attitudes expressed in class made them feel unable to ask for help. While schools had a grievance process in place to mediate situations where faculty or administrative staff unlawfully denied a student accommodations, this process was often confusing and long-winded; for example, if a student were to bring a complaint against a professor, the semester might have ended by the time a resolution was reached, making the whole exchange moot. Furthermore, this grievance process was often facilitated by the disability services office themselves or the school’s dean of students, even in cases where students had previously experienced bias from these offices. These factors made students unlikely to use the grievance system, and participants expressed that it felt as if they had no recourse if a professor was unwilling to accommodate them, in some cases forcing students to change their academic trajectory entirely if they were unable to avoid courses with unaccommodating professors.

### ***Stigma and Lack of Understanding***

The exchanges that students recalled with faculty reflect an underlying conflict within higher education: ableist ideas and attitudes surrounding disability. In the case of faculty, some may hold misguided beliefs that accommodating for disabilities gives disabled students “extra help” or an “unfair advantage” over their peers, when in reality it allows for students to have equal access to course content. This leads to an unwillingness to assist students with disabilities in succeeding in their courses. One student claimed that their professor felt “insulted” when they were asked to implement accommodations, because the professor felt that this insinuated that they were not teaching the course correctly.

Students cited that physical and sensory barriers they faced, such as bright lighting or excessive noise, made certain aspects of their campuses inaccessible to them. However, they clarified that these issues existed because of a larger hurdle: that students, faculty, and staff are unaware of these accessibility barriers or unwilling to make these spaces accessible. One expert elaborated that there still lingers the misconception that disabled students don’t “belong” in college, and this belief manifests in a multitude of practices that make disabled students less likely to enter and succeed in higher education. For example, professors who research

disability may discuss disability with a pathologizing lens, making students hesitant to identify as disabled. Microaggressions such as ableist language being used in everyday conversations contributed to feelings of social isolation for students, and inaccessible social spaces further alienated autistic students from their campus community.

As these compounding factors compel disabled students to keep their disability status to themselves and eschew asking for help accommodating their disabilities, this silence further feeds into the cycle of stigma that students face. Students identified feeling unable to build a disability “community” as one of the most salient barriers to their higher education success, as the negative attitudes relating to disability on-campus kept disabled students from connecting with each other in meaningful ways. Students with multiply marginalized identities felt especially conflicted because, while on-campus spaces existed for some of their marginalized identities, they did not feel that these spaces were welcoming of disabled students. For example, one student of color mentioned that their campus had a cultural center for students of color, but the space did not have cultural competence surrounding disability. As a result, the student did not feel welcome or included within the space.

Non-speaking autistic students in our sample identified additional barriers they face in higher education. People often overlooked these students as being unable to engage in conversation because it took them more time to type out their thoughts in comparison to verbal speech. One student expressed that they felt as if others presumed they were “incompetent” because of the misconception that non-speaking people do not have thoughts. Ideas about what a college student “looks like” can be damaging to students who don’t fit that mold, which is crucial to address as more and more non-speaking people attend college.

Another major source of stigma that autistic students faced stemmed not from autism specifically, but mental health disabilities. Many autistic people have co-occurring mental health disabilities, and the way that college campuses treated students with these disabilities was considered a major factor impacting student success. Participants identified a lack of support for students with mental health disabilities; schools that offered counseling services gave a limited amount of support, and often refused to serve students whose disabilities were considered too “severe”. In addition, students in mental health crisis were often forced to take medical leave from their schools, regardless of how this decision might impact their mental health, and faced resistance from administration if they tried to re-enroll following their leave. The fact that many schools would rather force students with mental health disabilities off of their campuses than provide them support illustrates the stigma that these institutions hold towards mental health disabilities, and reflects a startling trend on campuses across the United States (Bazelon Center, 2018).

### ***Hidden Costs of Disability***

Addressing all of the barriers elaborated upon above can absorb the majority of a student’s time, as well as take physical, mental, and financial toll on these students. One expert used the term “disability tax” to describe the extra efforts that disabled people must exert to accommodate their needs and be fully included. For example, we earlier identified the process students without a documented disability must complete in order to receive accommodations, which requires time to go through the diagnostic process, access to transportation to and from a diagnostic center, as well as money to pay for these services - many of which are not covered by insurance. Students whose mental health disabilities are deemed too “severe” for on-campus counseling must go through a similar process to obtain off-campus counseling services, and students with additional health needs, such as many autistic students with co-occurring physical health conditions, must do the same to manage their health. Focus group participants expressed the difficulty of juggling appointments that often conflicted with their class schedules, and left them without the energy or financial means to participate in many social activities that other students took for granted.

Autistic students may have additional accommodation needs that disability services offices won’t provide. For example, non-speaking students may need additional tools to communicate, such as an Augmentative and Alternative Communication (AAC) device, and students who need independent living support may require

a 1-to-1 aide. One student in our focus group who needs around-the-clock assistance expressed that they are only able to attend college because their family has the financial means to pay out-of-pocket for these services. Because many campuses offer disability services that are solely academic in nature, students who need support in social settings, with independent living, or in other domains may fall through the cracks. In addition, one participant mentioned that students who need to take a reduced course load due to their disabilities may not qualify for financial aid, placing an additional financial burden on these students.

Advocating for themselves within higher education institutions that were at times uncaring and occasionally openly hostile towards autistic students created another “cost” for these students: the toll of emotional labor. Participants claimed that they felt obligated to continually assert their right to exist in college as an autistic student, work towards improving their campus climate for disabled students, and attempt to create disability community. At the same time, these students also had to manage their own needs related to their physical and emotional well-being as a disabled person. All of these efforts occurred alongside the activities of a typical college student: managing a rigorous academic course load, maintaining a social life, living independently, and other activities to prepare for life after college (internships, volunteering, etc). For some students, the weight of all of these activities on their energy and emotional well-being was too much to bear, and coupled with a lack of support on-campus, led to these individuals dropping out of college.

In addition to the physical and emotional toll that comes from being disabled in higher education settings, many autistic students are also members of other marginalized communities, and face barriers during their college experience as a result of this. For example, an autistic student of color may face racism in academia, or when attempting to obtain a campus job or internship. If they come from a financially disadvantaged situation, this makes it even more difficult to shoulder the costs of accommodating a disability. These compounding burdens could mean that multiply marginalized autistic students are even less likely to have the support they need to finish college.

## **Addressing Structural Barriers**

### *Easing the transition*

Students identified the need for additional support as they transitioned into higher education. This included allocating additional time for autistic students to acclimate to their campuses and expectations within college. It also encompassed being able to access relevant information for disabled students, such as how to secure accommodations or what opportunities exist for social support. Transition programs for autistic students could be one way to address this need, as well as offer ongoing support through the early portions of a student’s college career (Shmulsky, Gobbo, & Donahue, 2015).

One expert, who facilitated a transition program for autistic students during their college career, explained how this model could be implemented to help ease the transition for this population. This program took place over 3 days shortly before the start of the Fall semester, in order to minimize activity on-campus and provide sensory-friendly space. Incoming students stayed overnight on-campus to become acclimated to dormitory living. The program was open to any student who identified as being autistic, regardless of whether or not they had a prior diagnosis, to acknowledge that lack of diagnostic services could be a barrier to participation. Clear information was provided to students about how to access disability services, including how to go through the grievance process if their accommodations were not followed. Some of the program activities included a “mock lecture” on the disability rights movement, which helped students learn about their community’s history while also understanding what a college course might look like.

Students within this program expressed that the experience helped them feel better-prepared for college. They also elaborated on additional benefits they gained from the program; they felt more positive about their disabilities through connecting with other disabled students, who also shared strategies on how they could accommodate themselves on campus. This opportunity also helped students build their own disability “community” of friends and allies before they even began their college careers.

### ***“Streamlining the bureaucracy”***

Students experienced major difficulties in receiving accommodations, from accessing the disability services office or diagnostic testing, to ensuring that professors follow these accommodations. Participants expressed a desire to mitigate these factors by “streamlining the bureaucracy”; that is, creating a centralized process for disabled students to receive the services and support they need. One idea students came up with was creating a disability services “hub” in the form of an online information center, that is displayed prominently on a college website and advertised directly to admitted students prior to starting school. Information about the location of the disability services office, what materials are needed to begin the accommodations process, as well as how to go through the grievance process are examples of what kinds of materials this resource could include.

Having a streamlined process could also aid students who find the traditional ways of requesting accommodations to be inaccessible. For example, one aspect of receiving accommodations that students had trouble with was needing to make a phone call to set up an appointment with disability services. Students who have auditory processing impairments or anxiety preventing them from using the phone may not be able to overcome this initial hurdle. By providing an online form to enter relevant disability information and request an appointment, more students would be able to access disability services. Additional information could also be provided about how to get a disability diagnosis, directions to the diagnostic testing site (if not on-campus), and guidelines for requesting on-campus transportation services or using public transportation to get there.

The idea of centralized support extends beyond just receiving academic accommodations: students articulated the need for clear avenues for access to additional services, such as counseling for mental health disabilities, or financial aid and scholarship opportunities for students with disabilities who shoulder additional costs relating to their accommodations (such as paying for a 1-on-1 aide or for diagnostic testing). As detailed in the previous section, information relating to the college transition process and/or employment resources for disabled students were also noted as areas that should be meaningfully incorporated into campus disability materials.

### ***Challenging ableist attitudes***

Ableism of both fellow students and faculty/staff were identified as an obstacle that negatively impacted the campus experience of autistic students. Participants stressed the need for college administration to take a proactive approach to addressing misconceptions that people have about disability. As one expert quoted, “Awareness only goes so far.”; in order for autistic students to feel welcome on-campus, concrete measures must be put into place that promote academic and social equity for them. Another expert detailed how the use of mandatory “educational equity” courses for faculty could be an effective method to teach disability competence, autism acceptance, and the framework of universal design for learning in order to make academia more accessible and inclusive. Having ongoing workshops for campus employees to learn how to best accommodate disabled students can assist in meeting the needs of these students, regardless of whether or not they have a diagnosis or receive formalized accommodations through disability services.

Modeling how to facilitate spaces and events that include disabled students was also cited as a way to foster autistic student belonging. For example, disability services offices might create access guidelines for student organizations to follow when planning meetings, or create their own events to discuss disability history and culture. As one expert detailed, the messaging that administrators use on campus promotional materials can also show that the college experience is for everyone, regardless of disability status; for example, campus websites can showcase both large and small events, and provide information about campus resources in accessible language.

### ***Building autistic community***

One of the most salient needs that autistic students expressed was the need for the tools to build autistic community. Students identified that having a network of autistic peers, or “community,” was integral to feeling a sense of belonging and purpose in college, as well as an opportunity to work through problems they might face

in college alongside other individuals facing similar issues. Participants stated that the most effective avenue for building this community was through the formation of disability student groups or cultural centers, as these spaces gave students the chance to socialize with other disabled students and engage in disability advocacy. These spaces also provided information and support to facilitate success in other areas, such as academic and independent living.

One expert expanded on this idea when discussing campus diversity and equity efforts. Many campuses have resource centers for marginalized communities, such as for students of color or LGBTQ+ students, but do not provide the same resource for students with disabilities. This expert emphasized the need for disability to be viewed as “a form of diversity”, and allocated similar resources that are given to other marginalized groups. At the same time, they acknowledged that, if the intersectionality of marginalized identities is not acknowledged within these resource centers, it can put different marginalized groups “at odds with each other”. Students agreed with this sentiment, and conversed about how different organizations for marginalized groups must collaborate with each other in order to create a truly intersectional campus community.

### *Centering autistic student voices*

Through all of the methods mentioned above, students and experts continually stated the need for the input of autistic students in the creation and implementation of these efforts. Students stated that they very rarely felt like they were “listened to” when attempting to improve their campus for autistic students, which impacted their decisions to continue their advocacy or leave college entirely. Students and experts agreed that the creation of advisory groups of students with disabilities were effective and crucial to the shaping of the agenda that campus administration should follow to facilitate autistic student success.

The centering of autistic students was considered especially important when it came to creating autistic community. Similar to the issues described earlier regarding autism research, many programs created to “support” autistic people view autism through a pathologizing lens, and center the priorities of non-autistic people. Students discussed how on-campus disability community efforts led by non-disabled students or staff generally did not align with the priorities of disabled students within these spaces. Oftentimes, these “communities” subscribed to a deficit model of disability, attempting to mentor students on how to minimize their disabilities rather than how to embrace their disabilities to augment their success. One expert, who facilitates an autistic mentorship program on their campus, illustrated how the development of a “group co-mentoring framework” could bolster the success of autistic students. By creating a problem-solving network of autistic peers from a variety of backgrounds, these students could collaborate to identify ways to accommodate their disabilities, as well as be active participants in improving their campus for other autistic students.

It is also important to note that, while ensuring that the voices of the autistic student population are the focus of any autistic inclusion efforts, this does not mean that the responsibility of improving the campus climate should fall on the shoulders of these students. As discussed previously, being a student with a disability oftentimes involves increased physical and emotional labor in comparison to non-disabled students. As group participants stressed, the primary responsibility of an autistic college student should be to focus on their own success, not to build an institution that facilitates their success; this responsibility falls on the campus administration. If an autistic student is solicited for feedback, their contributions should be acknowledged as an effort that goes beyond their duties as a student. For example, this acknowledgement could be in the form of creating a student employment position with appropriate compensation, or offering academic or community service credit.

### **Autism Support Programs**

Students and experts had mixed feelings when it came to autism support programs. They felt that whether or not an autism support program helped or hindered autistic student success came entirely down to the program structure and leadership. Since programs varied so widely among different educational institutions, students could have completely different experiences within programs that are ostensibly offering the same

“autism support”. For example, one student who participated in an autism support program praised the implementation of this specific program; it provided many of the resources that students advocated for in previous sections of this paper, such as access to mental health counseling, referrals to off-campus support services, campus orientation assistance, autistic peer mentorship, autism acceptance trainings for professors, and social opportunities. Another student within a different support program, which matched autistic students with non-autistic “coaches”, ended up paired with a student who did not help them achieve their goals, and was told that they were not allowed to change their coach. They felt that the mentorship model led to an unequal partnership that at times prioritized the desires of the mentor rather than the autistic student. This program did not have a dedicated staff member who supervised the mentorship pairs, and was not adequately funded by campus administration.

One expert, who oversees an autism support program at their college, stated that to their knowledge, they were the only autistic administrator of an autism support program; they cautioned against autism support programs led by non-autistic people, who might not understand what autistic people want and need from these programs. For example, many autism support programs focus on improving the “social skills” of autistic students, rather than identifying the goals of autistic students themselves, or educating the campus on how to accommodate autistic students in different social situations. While colleges may create these programs with good intentions, and it is a useful metric to display that a campus is dedicated to assisting autistic students, if the program does not center the priorities of autistic students and work to help them achieve their goals, these programs could instead be actively harmful to these students.

Even if a program does offer helpful services and supports to autistic students, there may be barriers that keep autistic students from utilizing these programs. Many autism support programs are a large extra cost on top of tuition, making these resources out of reach for those who can’t afford them (Longtin, 2014). These programs might also require an autism diagnosis to participate, which would leave out autistic students who did not have access to diagnostic services prior to entering college. These barriers deeply impact low-income students, who have less access to diagnostic resources or the ability to pay for additional on-campus support, as well as students who are women and/or people of color, who may be unable to obtain an autism diagnosis due to misconceptions about who can be autistic. Autism support programs may also have additional requirements that violate the privacy and dignity of students. For example, one student mentioned that the autism support program on their campus required applicants to provide sensitive medical information, as well as prove they meet certain “functional criteria”, such as the ability to speak, in order to gain access to the program.

A few experts also acknowledged that the existence of programs specifically for autistic students could lead to unintentional segregation of these students from the broader campus population. One expert stated that autistic students may not want to be recognized as “that student in an autism support program” since that can lead to being ostracized by other students and negatively affect their sense of belonging. In addition, as one student expressed, some of these programs focus more on offering a “college experience,” placing students on a non-degree path and providing segregated social opportunities, rather than helping students work towards a degree while building meaningful relationships with non-disabled students. The overall consensus was that the idea of having a separate program “just for” autistic students may not be the most effective way to address the needs of these students. As another expert summarized, administrators of autism support programs may believe these programs are the “best case scenario” for autistic students; however, it is the legal responsibility of college campuses to provide equal access to education for students with disabilities. Providing programs for autistic students that cost additional money, while not providing the same opportunities that non-disabled students have, violates the Americans with Disabilities Act. Campuses must consider how they will uphold the standards of the law if they choose to administer support programs for autistic students.

## Discussion

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Participants in our survey elaborated on a number of ways to define and measure success that go beyond the traditional ideas and methods. Rather than focus on retention, graduation, and academic achievement, self-determination, student inclusion and satisfaction were considered to be more important to feeling successful for autistic students. Previous literature identified these factors as contributors to success, but not as being measures of success in themselves; for example, one study found that teaching self-determination skills and having a coordinated system of supports to aid in full higher education inclusion helped increase retention and graduation rates for students with disabilities, with retention and graduation being used as a metric for success (Yeun & Shaughnessy, 2002). Our findings necessitate creating new measures that encapsulate success in the ways defined by autistic students and experts.

In addition, employment outcomes received increased focus from autistic students and experts. Research asserts that lack of employment opportunities is a critical area for improvement for disabled students in general; one study found that 84% of non-disabled college graduates found employment post-graduation compared to 53% of graduates with disabilities (Huber, Oswald, Webb, & Avila-John, 2016). Autistic students may face additional barriers to achieving employment success, as many reported that their campus career services offices were not able to adequately assist them due to a lack of understanding about autism (Gelbar, Shefcyk, & Reichow, 2015). Campuses may be able to gain a better understanding of the success of their autistic alumni through collecting data on employment outcomes, which could be used to improve the experiences of current and future autistic students.

When discussing barriers to success, great emphasis was placed on the difficulty of receiving adequate accommodations from disability services offices. Existing research agrees that the process of requesting accommodations can be a daunting task for autistic students, especially for undiagnosed students (Adreon, & Durocher, 2007). This situation is exacerbated when faculty and staff refuse to accommodate the needs of these students (Decker, Lloyd, & Morlock, 2011). The 'laundry list' approach of offering accommodations has also been criticized in other studies, with one finding that little evidence exists that the standardized list of accommodations leads to improved academic performance (Rath & Royer, 2002).

Participants further elaborated on the accommodations they needed in non-academic spheres that their colleges did not provide, presenting an additional roadblock to their success. The majority of students expressed that their campus practices negatively impacted their feelings of inclusion and social belonging. These findings align with previous research that reported that autistic students felt that while their academic needs were met by their colleges, their social needs were not (Cai & Richdale, 2016). Additional data depicted that many institutions of higher education neglect to focus on how social opportunities impact the student experience (Fleming, Oertle, Plotner, & Hakun, 2017). Increasing their focus on non-academic accommodations and social support is crucial for colleges and universities to create a welcoming climate for autistic students.

Preconceived notions about what autism means and how autism should be addressed within higher education led to conflicted emotions amongst autistic students and experts. Students felt that negative or ignorant attitudes about autism were a major contributor to inaccessible and non-inclusive spaces on their campuses. These attitudes are reflected in the way that autism is framed by these institutions, and relates to whether or not autistic people are meaningfully included in these conversations and/or given the tools to conceptualize and achieve their own goals. One study found that websites for higher education institutions often mentioned autism in demeaning ways, or only referred to autism when referencing volunteer opportunities or charity events; this study also found that text written by and for autistic people was absent from all but one website (Nachman & Brown, 2019).

The deficit-based ideas that college and universities hold surrounding autism could influence what kinds of services are offered to students within autism support programs. In a survey of these programs, it was found that the service offered by the highest number of institutions was "social skills" training (Barnhill, 2016). The

idea that autistic people need this type of training is tied to the deficit model of autism, and does not reflect the desires and goals of the autistic students we surveyed.

Misconceptions about autism lead to a de-centering of autistic voices, which allows these misconceptions to continue and further harm autistic students through leaving their needs unaddressed. In order to break this cycle, higher education institutions must evaluate how they are currently serving autistic students, and meaningfully incorporate autistic feedback into this discussion. Even if a school already has an autism support program in place, depending on the implementation, it may behoove them to radically alter the program or discard it entirely in order to bolster autistic student success.

While the feedback we obtained is invaluable to re-envisioning higher education experience for autistic students, the participants within our survey did not include students with intellectual disabilities. As a result, we are lacking information about how this critically underserved population envisions their success, as well as insights as to how programs that specifically serve students with intellectual disabilities (such as TPSIDs) practice in ways that aid or hinder achieving this success. In addition, the experts who were interviewed for this paper did not include autistic people of color or autistic people with intellectual disabilities. Racism and ableism within the field of disability studies often deny members of multiply marginalized groups the opportunities to become “experts” within this field. We aim to further center and prioritize the voices of autistic people of color and autistic people with intellectual disabilities in future iterations of this paper.

## Core Principles for Autistic Student Success

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As evidenced above, a wide variety of elements impact the success of autistic college students, and higher education institutions will need to adopt a comprehensive approach in addressing these factors. While the purpose of this paper is not to outline step-by-step how to implement campus reform to positively impact autistic students, we aim to provide a framework that campuses should be mindful of when considering how to serve their autistic student population. Building on the feedback provided by autistic students and experts through our survey, we present the following 10 core principles that the autistic population identified as keys to their success, alongside basic recommendations as to what implementing these principles might look like:

**1) Make disability an institutional priority:** Create intentional space for disabled students (such as a disability cultural center). Create an advisory board to evaluate how your campus can best serve disabled students. Commit financial resources to better support of disabled students, including ensuring an appropriate number of staff for disability services.

**2) Focus on accessibility:** Create spaces that are physically, sensorily, and socially accessible to autistic students. Provide guidance to students, faculty, and staff on how to create accessible and inclusive spaces for autistic people.

**3) Student-centered accommodations:** Provide disability services that help students achieve their goals, whether those be related to academic achievement, social inclusion, independent living, career development, or other aspirations. Be open to non-traditional methods of accommodation. Consider how to serve autistic students in areas outside the classroom or disability services office (such as in campus employment or career services).

**4) Facilitate social inclusion:** Create social opportunities for autistic students that prioritize the development or organic, equitable relationships between autistic and non-autistic students. Be wary of offering programs that could lead to unequal relationships, such as pairing autistic students with non-autistic peer mentors.

**5) Develop centralized information:** Provide clear information regarding disability services, including methods to access services, obtain documentation, etc. Create resources to aid autistic students in their transition to higher education. Avoid deficit-based language in any campus publications. Advertise relevant information widely and often.

**6) Ensure cost parity:** Whenever possible, provide free or low-cost on-campus resources for common accommodation needs (such as mental health services or diagnostic testing). If this is not possible, create avenues for disabled students to receive financial support (such as through a dedicated fund or scholarships). Evaluate financial aid services to ensure all disabled students qualify for assistance.

**7) Foster cultural competence:** Evaluate existing campus programs, such as centers for students of color or LGBTQ+ students, to improve accessibility and feelings of belonging for disabled students. Promote cross-cultural learning opportunities between disability-specific programs and programs that serve other marginalized groups. Hold regular workshops surrounding disability competence and autism acceptance - including within disability services office.

**8) Implement additional supports:** Offer accessible mental health services that accommodate all students, regardless of the level of support needed. Offer assistance with independent living supports and diagnostic testing, including transportation resources for any off-campus resources.

**9) Include all autistic people:** Ensure that on-campus services and spaces account for a variety of support needs. Be mindful of students who are more likely to experience exclusion, including non-speaking autistic students, autistic students with intellectual disabilities, and multiply marginalized autistic students (such as autistic students of color). Be cautious of offering programs that may segregate autistic students from the wider campus population, such as autism support programs.

**10) Center autistic voices:** Create opportunities for autistic students to meaningfully influence how your institution can better serve them. Involve autistic people in the creation of disability-related materials and cultural competency trainings. Value the expertise that autistic students offer through lived experience through creating student employment opportunities, autistic peer mentorship programs, etc.

## Conclusion

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Autistic students and higher education experts expressed unique insights on how they envision autistic student success and how college campuses can support this success. While some of these ideas aligned with previous higher education literature, other ideas, such as measuring success through student satisfaction and questioning the necessity of autism-specific support programs, challenge the prevailing concepts on how autistic students should be served in order to facilitate their success. The core principles outlined above, created with the assistance of the collected feedback, are the first steps to creating colleges and universities that have optimal conditions for autistic students to fully participate and succeed in higher education. We encourage higher education administration to keep these principles in mind as they seek to attract, retain, and accommodate autistic students at their institutions.

While some of these recommendations would place little to no financial burden on higher education institutions, others would require substantial financial investment. As individuals with disabilities have been so often relegated to situations of financial inequity, leading to many disabled people unable to access college altogether, it is imperative that campuses acknowledge these structural inequities and work to address them. Furthermore, there is a strong financial incentive for colleges to improve their campuses for autistic students; by displaying how their campus supports these students in their higher education endeavors, autistic student enrollment and retention will be increased, generating additional tuition alongside additional funding opportunities from public and private entities.

Further research is needed on how these core principles can be translated into steps for implementation and measurable goals for higher education institutions. Throughout this process, we urge researchers to incorporate a participatory framework that meaningfully incorporates the feedback of autistic students. Facilitating autistic student success is not possible without considering the wants, needs, and goals of these students, and creating measures that help them achieve success as they define it.

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