PERSPECTIVES OF PRIORITIES FOR SUPPORTING COLLEGE STUDENTS ON
THE AUTISM SPECTRUM

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by

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INTRODUCTION

The Centers for Disease Control (CDC) estimate a 21% increase in autism diagnoses among children born in 1996 compared to children born four years prior. As diagnoses of autism and understanding of disability rights continue to increase, individuals on the autism spectrum and others associated with these group lead efforts to improve inclusion in a wide range of community life including work, recreation, civic engagement, and education. This increased interest to better include people on the autism spectrum in community life has contributed to a growth in the number of Autistic\textsuperscript{1} students who are seeking post-secondary education opportunities. For example, the National Autistic Society reports a 35% rise in post-secondary enrollment of Autistic students. Additionally, efforts to better include individuals on the autism spectrum in community life have led to changes in service priorities related to autism as the groups who have historically driven the dialogue have shifted. Where family members and

\textsuperscript{1} I follow the example set by Sinclair (1999) with more frequent use of identity-first language (e.g. Autistic people) than person-first language (e.g. people with autism). The American Psychological Association recommends that academic authors “respect people’s preferences; call people what they prefer to be called” (APA, 2001, p. 63). Identity-first language is widely preferred by the Autistic self-advocacy community. In the event that a person being quoted or referred to prefers person-first language, they are referred to accordingly in this paper.
professionals were once the primary source for identifying service priorities about autism, Autistic people are now advocating to have their voices heard.

Past Practices

Previously, the focus for services was centered on cures for autism and ways to aid people on the autism spectrum to conform to and fit into society. Recently, Autistic individuals are advocating to instead promote acceptance of a culture of autism (Sinclair, 2005). The differing priorities for direction of services can lead to problems such as inaccurate portrayals of autism, misuse of resources, and unmet needs of Autistic people. In the post-secondary setting, this could mean initiatives aimed at supporting Autistic students that might misrepresent, inadequately support, or even alienate them on campus.

Autism Rights Movement

The expansion of the disability rights movement posits that inclusion in society, including post-secondary institutions, is a right to which people with disabilities are entitled. As the number of college students on the autism spectrum increases, it is important to explore their perspectives and the perspectives of family members as well as those who provide post-secondary services to them regarding service priorities. Such exploration enriches understandings of their needs as college students. Thus, this study aims to contribute knowledge to disability studies, autism research, and service delivery systems by increasing the understanding of post-secondary needs for students on the autism spectrum to be successful in college to graduation and to promote greater academic and social inclusion on college campuses.
Autistic College Students

According to the American Psychiatric Association (2013), common characteristics of autism include difficulty forming and maintaining relationships, discomfort in social situations, and reliance on routines. The often social, go-with-the-flow atmosphere of college can be difficult to navigate for people on the spectrum due to the social challenges and rigid tendencies that often accompany autism. While many experienced similar challenges in high school, college is a new physical and social setting that can present different obstacles. When needs go unsupported, difficulties in other areas, such as anxiety and depression, may develop (Pinder-Amaker, 2014). Thus, it is important to understand perspectives on ways to support Autistic students as they navigate this transition so that these supports may be provided in the most successful way possible. Given the rise in number of Autistic students seeking post-secondary opportunities (National Autistic Society), several recent studies have investigated various perspectives on the college experiences of Autistic students.

Perspectives of Disability Service Professionals

Studies regarding the experiences of college students on the autism spectrum are a relatively new area of research with the majority of studies being conducted from the service professional or faculty perspective. Some studies provided a snapshot of current practices, including social-skills groups and residential programs, for supporting Autistic students on campus while others addressed academic accommodations. Krell (2012) surveyed disability services professionals who had experience with facilitating Autistic college students’ transitions to postsecondary environments. These participants identified
29 things school counselors can do to help prepare Autistic students for college. These findings include but are not limited to encouraging students to be involved in planning for the transition to college, collaborating with parents, holding workshops for students and their families to help guide the transition, and encouraging self-advocacy. Though this study provides detailed recommendations on part of the transition process, it investigates only a small portion of those involved in this process, leaving many other perspectives and factors unexplored. Additionally, though the study presents many recommendations for transitioning to college, it provides little insight into what supports are currently provided to Autistic students or what Autistic students feel they need to successfully transition.

Brown and Coomes (2015) conducted a study with disability service professionals examining best practices for supporting Autistic students at 2-year public, postsecondary institutions. Using a web-based survey, they asked subjects to identify supports currently available to Autistic students to understand best practices for supporting Autistic students at these colleges. The authors found that while basic academic accommodations were commonly identified as a best practice, most institutions did not offer supports specific to sensory and functional needs that might be pertinent to the lives of many Autistic students. The authors recommend future examinations testing the effectiveness of various supports and best practices as well as conducting an exploration of Autistic college students’ perspectives on supports.

In an exploratory study, Barnhill (2016) examined holistic supports for Autistic college students from the perspective of disability service professionals, such as support
groups, social activities, and transition programs. The results included a recommendation for collaboration with and inclusion of many perspectives in providing well-rounded supports for Autistic students. Barnhill suggested further research from different perspectives to better understand diverse ideas about support needs and ways in which these perspectives factor into overall supports. Additionally, the authors note that since so many supports are still in their incipient stages, further research should continue to investigate student needs and the effectiveness of supports as they develop.

*Perspectives of Faculty Members*

Professionals aside from disability service providers also play important roles in providing support for Autistic college students with their college experiences. McKeon, Alpern, and Zager (2013) conducted a pilot study in which they surveyed university faculty members on a single campus about their understanding and expectations related to students with disabilities – including Autistic students. Many faculty noted observing these students experiencing difficulties with communication in the classroom, sometimes to an extent that the difficulties created acrimony with peers. Professors also noted that executive functioning skills such as time management and impulse control were sometimes areas of struggle for students with disabilities. However, they often noted that their responses related to only a small number of students with whom they had interacted – a small subset of the much larger pool of all students with disabilities. They saw students with disabilities as an overall heterogeneous group, which, while ideal in terms of recognizing diverse needs, made generalization difficult. Many professors also reported using teaching strategies to help support students with disabilities. The authors
note that more support is often needed to help faculty understand how to best provide supports and that this training should focus in particular on classroom strategies to help support executive functioning and appropriate behavior. While this pilot study provided insight into faculty perspectives on autism (and other disabilities), the authors note that further research should plunge more deeply into professors’ experiences and into what supports they need in order to be able to provide adequate supports for their students.

A study by Gobbo and Shmulsky (2014) delved more deeply into faculty perspectives through focus groups. Gobbo and Shmulsky examined the experiences of faculty who have had Autistic students enrolled in courses they taught on students’ challenges and needs in classroom settings. The results were similar to those found by others in that foci were on difficulties in classroom communication and executive functioning skills. The focus group method allowed participants to express a wider range of viewpoints and ideas compared to previous survey-based studies thus yielding greater detail and depth. However, the classroom experience is only a small portion of a successful college life, and research of similar depth but broader scope could illuminate other areas of the college experience in which Autistic students could benefit from support.

*Perspectives of Autistic Students*

Recently studies have been conducted to understand the college experience from Autistic students. Gillespie-Lynch, Bublitz, Donachie, Wong, Brooks, and D’Onofrio (2017) designed a program for college students on the autism spectrum to address areas in which these students often report challenges, such as social skills and self-advocacy.
They found that those who participated in social-skills groups reported a reduction in anxiety on the Spielberger State-Trait Anxiety Inventory and participation in self-advocacy groups often led to more perceived social support, according to the students, as well as to belief in their own academic abilities and more accurate understanding of self-advocacy. Though this study’s nature of focusing on only a few specific supports for students at a single college causes it to be somewhat narrow in breadth, it offers evidence for specific types of supports that can be helpful to students on the autism spectrum. The authors posit that Autistic college students’ input is crucial in developing supports and that future studies should make a concerted effort to include their perspectives.

Gelbar, Shefcyk, and Reichow (2015) conducted an online survey of thirty-five students on the autism spectrum to learn about current campus resources that could be improved in order to provide support. While many of the students reported benefitting from the academic supports they received, they noted a need for more support in the social and emotional aspects of their college experience. Specifically, students reported much higher rates of perceived academic success than social success. While many students reported perceived support and understanding from disability service coordinators, far fewer reported similar levels of support and understanding from general campus services such as career services and study abroad offices. Future studies could build on this study’s findings to examine supports that could be beneficial in all areas of campus life and provide a more complete picture of the needs of Autistic students. Additionally, the authors note a lack of research on the lived experiences of Autistic college students and suggest that future research should focus on these experiences.
Using qualitative methodology, Cullen (2015) interviewed 24 students on the spectrum about their support needs and experiences with campus resources. Results were separated into areas of social needs, academic requirements involving group work, and daily living needs. While students reported some academic needs, their needs were largely related to social challenges such as social issues with group project requirements. The students surveyed raised a wide range of social difficulties that may go unconsidered in many settings. For instance, one respondent reported struggling with transportation due to the difficulties anxiety presented in using the bus system. Students reported that their needs were met primarily through family, school, and social media. All of these areas, however, appear to be organic supports (e.g. student groups providing opportunities to meet like-minded students) rather than accommodations made by colleges and universities for students with disabilities. While identification of these supports provides excellent insight into areas of the college infrastructure that can naturally aid Autistic students, further investigation into areas of intentional support could provide a more complete idea of what supports could be provided to further facilitate success.

Ackles, Fields, and Skinner (2013) discussed the importance of meeting a wide range of needs of Autistic students in a holistic way. They recommend fostering a welcoming environment and positive attitudes toward autism and disability rather than solely focusing on requiring Autistic people to adapt for college. These ideas, which deal with adapting college systems to meet a wide range of needs in a way that is consistent with the principles of universal design (Longtin, 2014) may be better suited to meeting the needs of more students than specific supports are. As Hammond (2015) notes,
invisible disabilities such as autism often carry a stigma that may prevent people from gaining access to the resources they need. However, there is a dearth of research surrounding the attitudes and needs regarding holistic support of college students on the autism spectrum. Such research would involve learning about the perspectives of several groups involved in supporting Autistic students, including Autistic students themselves, about their beliefs and perceived roles in supporting these students.

Thus, the purpose of this study was to investigate perspectives on the overall needs of Autistic students with increased focus on Autistic voices and on the experiences that shaped respondents’ conclusions.
METHODS

This study used a qualitative methodology to understand different perspectives on what constitutes a successful college experience for an Autistic student and what supports might be needed to create that successful college experience. A qualitative approach was beneficial in addressing the research questions because it allowed participants to share their unique experiences and perspectives as fully and accurately as possible.

Interview Guide

The interview questions seek to get an understanding of each participant’s background and relation to autism, perception of autism, views on self-advocacy, ideas about supports toward better inclusion, and considerations of support as a pathway to inclusion and acceptance. These questions were designed with the goal of understanding the participants’ backgrounds, perspectives, and goals, the ways in which they were similar or different, and identifying ways in which autistic college students may be supported on campus. Questions regarding supporting inclusion and community involvement were developed using previous literature (Ackles, Fields, & Skinner (2013); Longtin (2014), Pinder-Amaker (2014). These articles were selected to guide the interview questions as they were the most useful in identifying the needs of students on the Autism Spectrum as they transition into college. Other questions that focused on acceptance, especially contrasted with awareness, and on inclusion stemmed from the writings of Autistic people including Dekker (1999), Evans (2012), Sequenzia (2012),
and Sinclair (2005) that illuminate differences between the way many Autistic people see themselves and the surrounding world and the overall public ideologies. Considering—and perhaps eventually bridging—these differences seems to be an important step in improving supports for people on the spectrum. See Table 2 for the main questions asked to participants during the interviews.

*Research Participants*

A critical component of this study is understanding the perspectives of those on the autism spectrum, thus two Autistic college students over the age of 18 were interviewed. Additional perspectives from people who were not students on the spectrum allowed for comparison among experiences and a more complete representation of the various perspectives at play. Others interviewed were two parents of Autistic college students, two professors who have had at least one student in their class whom they were aware was on the spectrum, two therapists who provide services to youth, adolescents and young adults on the autism spectrum, and two university staff members who have a general understanding of autism, but not extensive experience. Table 1 contains the pseudonyms of each participant and a brief description of their role.

The study was approved through the university’s Institutional Review Board. Participants were identified through personal connection and through an on-campus advocacy group and were recruited via email. Potential participants received an initial email explaining the study and why their participation would be valuable. Recipients from whom a reply was not received were sent the same email once more as a reminder.
Upon replying with interest to the email, potential participants were asked for their
availability, and an interview was scheduled at a time that was convenient for them.

Data Collection

I met with each interviewee individually on the Kent State University Kent
campus over a one-month period in the spring semester. The interviews were at a time
and location that was convenient for the interviewee, and all were conducted in private.
Faculty, staff members, and therapists were typically interviewed in their offices, and
students and parents were usually interviewed in one of the private study rooms in the
campus library. Interviews ranged widely in length according to the detail respondents’
offered. The shortest interview was about twelve minutes, while the longest ran for
approximately one hour and six minutes. The average length was thirty-one minutes.
Requests for clarification were made as necessary throughout the interview and
participants were not contacted again once the interview was finished.

Data Analysis

The interviews were recorded and were later transcribed. The transcriptions were
then analyzed via the constant comparison method for similarities and differences in
themes of the answers. Participants’ ideas about themes such as culture, self-advocacy,
and campus success were grouped together. These ideas were then compared to those of
other participants. Additionally, commonalities amongst answers were linked to
overarching zeitgeists related to autism, such as the concepts of autism acceptance and
autism awareness. Thesis Advisor Dr. Mary Ann Devine reviewed the transcriptions and
themes, noting any areas of disagreement, which were resolved through conversation.
RESULTS

As an increasingly large number of Autistic students enroll in college, more focus is devoted to understanding their needs and how those needs can be met. Based on dialogue about autism that takes place in a variety of settings, there appears to be a wide range of perspectives on the needs of Autistic students. To contribute to better understanding of these perspectives and what experiences might shape them, two therapists, two parents, two professors, two university staff members, and two Autistic students responded to a variety of questions about their experiences and perspectives. This exchange took place during a one-on-one interview with the researcher covering several noteworthy topics related to autism throughout the interview. Overall, their responses can be divided into perspectives on culture, self-advocacy, and succeeding and engaging on campus.

Culture

The way people with disabilities view themselves in relation to the world around them is a large part of disability culture (Brown, 2002). As Autistic culture, a subset of disability culture, continues to grow and develop (Dekker, 1999), perspectives on Autistic culture are helpful for understanding autism as a disability and serve as a rallying point for a burgeoning community. Keeping with the larger disability culture, Autistic culture comes with specific language, values, and traditions to which its members generally subscribe.
Use of identity-first language (Autistic person) as opposed to person-first language (person with autism) is a hallmark of Autistic culture. Some find this difference of wording to be unimportant. However, it has been known that the words people use to talk about things can both reflect and influence perspectives. Those on either side of the debate regarding identity-first language versus person-first language typically use this fact in support of their stance. For example, supporters of person-first language often cite feelings that putting the disability first can cause people to draw upon prejudicial ideas of disability and influence their attitude toward the people being discussed (Tobin, 2011). Others, particularly those with recent involvement in the disability rights movement, like Jim Sinclair (2012), autism-rights activist and founder of Autism Network International, disagree. Instead, they postulate that identity-first language is important to framing disability as an element of diversity that is not shameful or wrong. There remain, of course, some people who are entirely unaware that such a debate exists - they have never realized any difference between person-first language and identity-first language. Others still are aware that there may be differences and still lack a strong preference. This study found disagreement over direction and strength of language questions as well, though the disagreement found was not between Autistic people and non-Autistic people. Specifically, both therapists and one university staff member preferred person-first language. One therapist, Amanda, explained “put the person first is usually how I was taught.” Of the parents, one preferred identity-first language. Of those interviewed, the students, professors, one staff member, and one parent expressed no preference. These differences in preference demonstrate the spectrum of views on Autistic culture as it
relates to discussion of autism by non-Autistic people. As the therapist noted, curricula often teach that person-first language should be used. However, the range of preferences represented by those interviewed indicates that preferences amongst the people in various communities may not be as straightforward as many textbooks would present them to be.

Interestingly, one parent and one professor seemed very hesitant to call autism a “disability.” Jessica, a parent of a college student who is on the spectrum, said, “It is not a disability, which a lot of people think it is. I’ve always explained it as something positive. It’s an evolution for the good of humanity.” Joan, speech pathologist, aims for “an identity shift from disability to diversity.” There has been a push within the disability community, particularly in the past few decades, to recognize disability as a branch of diversity (Shapiro, 1993). However, these responses seemed to take the idea a step further by separating disability from diversity and instead holding deemphasizing disability as a priority for the successful inclusion of Autistic people in universities.

Despite varied responses regarding other aforementioned aspects of culture, participant perspectives seem strikingly similar regarding the difference between autism awareness and autism acceptance. Historically, and still prevalent amongst many major autism organizations, the focus has been on “awareness,” which many self-advocates, such as those at the forefront the Autistic Self Advocacy Network, explain tends to be passive, employ fearmongering, and do little to immediately benefit autistic people. These advocates push instead for “acceptance,” which they posit as an active process that inherently makes the world more accessible (Evans, 2012). Interviewees’ responses seemed to echo these advocates’ sentiments. Many mentioned that awareness seems like
a point on the road to acceptance, but also voiced that awareness in itself is not enough. As Professor Amelia put it, “that’s a vast gap. I think people can be aware of many things, but maybe not as accepting as they should be. I think that’s something that we’re going to have to work with. I think that’s important. I think that’s very important. We have to move into that notion of acceptance.” Theresa, a senior, explained, “In my experience, autism awareness has been more Autism-Speaks-type stuff, and the whole thing is like being aware of how bad it is for them and their families and donate to this thing to cure it and stuff, and ... autism acceptance is more accepting that people have autism and that it’s not a bad thing and more helping things be more accessible to them.”

**Self-Advocacy**

Historically, self-advocacy has been a major factor in the disability rights movement (Shapiro, 1993). Self-advocacy can look different across a wide variety of people and situations, and it remains an important topic in disability rights. Participants were asked to define self-advocacy and speak to its importance as it relates to Autistic people. Overall, while those interviewed seemed to agree that self-advocacy is important for all people, including those on the autism spectrum, the focus of their responses seemed to vary widely based on respondents’ roles in and understanding of the Autistic community. Respondents who were staff members, therapists, and professors all discussed self-advocacy in terms of an individual’s ability to have their needs met, indicating that this is a primary priority for them. One therapist, Joan, started out by describing a self-advocate as “someone who can effectively get their needs met.” Joan clarified and expanded her meaning of “need” by continuing,
“Self-advocacy is important for many reasons I think. One has to do with self-esteem. That people who can advocate for themselves are likely to have better self-esteem. The other is autonomy and independence. If you can advocate for yourself, you can increase your level of independence. And also identity. If you can advocate for yourself, I think you get to shape your identity instead of having somebody put an identity on you.”

Both students discussed the importance of self-advocacy in allowing Autistic people to connect with and support each other, and to control the narrative surrounding autism.

Alec said:

“The nice thing about self-advocacy is that more people with autism are able to connect. When you get a bunch of people that are able to connect, you’re going to see a lot of different people that are able to work off of each other, because one person who has autism might have a solution to another problem that I am experiencing.”

As Alec pointed out, self-advocacy can allow people to understand and communicate their own experiences in a way that allows for connection with and support from others. Theresa ventured, “we need voices that are people with actual autism and not neurotypical people, I guess, because they are mostly who dominates the conversation about these things at this time.” Their responses suggest that connections with other Autistic people and with others who are discussing autism are priorities for them.
Both parents’ responses reflect a focus on the importance of self-advocacy as a means of self-expression and interaction with others. In Maggie’s words,

“I think that for a long time, I was assuming what [my son’s] needs were because his ability to verbalize or to express to me were lacking, or I wasn’t understanding his communication when sometimes it would come out in the form of maybe what looked like a temper tantrum or explosive behavior - or sometimes just retreating and being silent - and so I spent many years trying to figure out what it was that he was trying to communicate to me and probably oftentimes missing communication, just not realizing that that’s what he was doing, and now as his verbal abilities are increasing, I am excited to hear him tell me what his needs are, and so I think that it’s also empowering for him.”

Regarding how self-advocacy can be supported, respondents offered a wide array of suggestions. “Being curious and listening” was the simple answer given by one therapist, Joan. While her focus was on supporting self-advocacy as it occurs, the other therapist, Amanda advocated an instructional approach to developing self-advocacy skills, using therapy techniques such as video modeling, role play, and social stories to help students fine-tune their self advocacy skills. Amelia, a professor, demonstrated that curiosity saying, “I imagine that in a place like a school we could perhaps be informed [about potential needs of students on the spectrum], and the first step would be something like an information session [for non-Autistic people to learn more about autism].” Her response was similar to Joan’s in that both recognized honoring advocacy as an essential part of supporting advocacy. Theresa, a student on the spectrum, and Madeleine, a
university staff member, specifically pointed out the difference between intentionally making space for Autistic voices and just listening politely when they happen to be there. Theresa, explaining that supporting self-advocacy involves actively seeking out and listening to the voices of self-advocates, commented that self-advocacy is supported “by neurotypical people being able to base their support of people with disabilities by listening to what the people with those disabilities have to say and going off that instead of making their own ideas of it.” Madeleine’s sentiments as a staff member reflected similar ideas: “I think oftentimes, we talk over people instead of really listening to what their needs and interests are ... I think we do that a lot in Higher Ed. We see issues and decide how to fix them instead of going to that population and pausing to make space for that voice and to value it.” Overall, these answers illustrate a variety of intertwining perspectives about when, where, and how Autistic students can best be supported in their self-advocacy. These perspectives seemed to overlap and run the gamut from simply listening to self-advocacy when it happens to teaching skills that allow it to happen more frequently to seeking out the voices of self-advocates.

The sources from which a person obtains information can also offer insight into their perspectives, including what influences those perspectives. For instance, as Theresa and Madeleine noted in the previous question about self-advocacy, information from people directly affected by an issue (in this case, Autistic people) can often be different from information from those not directly affected. Given the wide range of potential sources, participants were asked what resources they have utilized to inform themselves about autism. The majority of respondents reported using academic articles and
professionals (e.g., therapists, healthcare professionals) who have experience with autism. Amelia said that her understanding of autism has come from “reputable websites – not things that looked fly-by-night, but things through medical links.” Michelle stated that she has not intentionally researched autism, but instead has received most information from popular media. Madeleine has learned about autism from friends who have one or more children on the spectrum. The only two respondents who explicitly mentioned seeking out information from Autistic people were the two Autistic college students. Theresa noted reading the Autistic Hoya blog and following the Autistic Self Advocacy Network closely. Alec, who enjoys learning from books, recommended several by Autistic authors, including John Elder Robinson’s *Look Me in the Eye*. He elaborated, “A lot of self-advocates tend to write books about their experiences, which help me learn about different aspects for myself.”

**Succeeding and Engaging on Campus**

A crucial part of understanding perspectives on autism is knowing what supports might aid Autistic people to be engaged on campus and succeed academically to graduation. Participants listed a wide variety of potential supports for these students. Some included creating opportunities for self-determination and the pursuit of feeling valuable, orientations and other resources to help clarify what resources are available, proactively planning for what accommodations might be necessary and making them readily available, and a strong and flexible support system. Theresa, a student, cited availability of online classes as an academic support that would benefit her. As for what could be counterproductive, both parents mentioned that a lack of support from
Administration could be a major hindrance to otherwise helpful initiatives. One parent, Maggie, said that it can be problematic

“If you’re not being supported from the top. If the president of the university doesn’t realize that there’s a need, if the professors don’t realize that there’s a need, if the resident adviser doesn’t realize that there’s a need, I mean any area where that student is going to be participating needs to have the supports in place for that student and any and all Autistic students that are involved in that activity.”

The other parent, Jessica, corroborated this idea, mentioning that it creates a problem “when the administration does not realize but there is a need, and the people who need to get the services are told that there is no funding to get these things.”

Inadequate preparation for new challenges presented by college life (e.g. larger class sizes, living with a roommate, etc.) was mentioned as a source of difficulty by Amanda, “I’d say the counterproductive piece might be a lack of thinking in front of the train of what could come at you that you aren’t prepared for. So you might get some negative situations that happen and that taint that child to want to be in those college classes because they weren’t really knowing what might not work for them.” Amelia, a professor, raised a similar idea in that forcing students to do things too far out of their comfort zone can be very harmful. She explains, “I do know [professors] that will score how often some students raise their hand and contribute to the group discussion, and I think that some students can get just as much out of a group discussion by listening and
they don’t have to necessarily make a contribution. Maybe they could make a
contribution on a scrap of paper...I’ve probably hurt people without even realizing it.”

A quote from Theresa can serve as an example of a situation that may cause
unintentional harm to students. She specifically noted “the focus on Autism Speaks” as
something that is counterproductive in that it “perpetuates the idea that we’re these
helpless beings that need to be cured and need so much help from the wonderful
neurotypical people.” Her idea seems to extend to the concept that the medical model of
disability, which focuses on changing the person with a disability to fit in better with
society, can be harmful to students on the spectrum.

Both staff members mentioned that being closed-minded about the needs of or
unwelcoming to students on the spectrum can prevent them from getting the
accommodations that they need. As Abigail put it, “Denying that it exists, or any of the
negative pieces that some people feel when it comes to either autism or really any
disability [can be counterproductive].” Madeleine added, “I think counterproductive in
supporting them is minimizing their value in terms of not meeting those needs. I would
think that would be detrimental to their success and comfort and sense that they’re
welcome here.” Speech therapist Joan suggested that sticking with the current “disability
model” can be counterproductive. She explained,

“ten years ago, I started a social skills group here for our college students on the
spectrum. They were done with that kind of therapy model. I think rightly so. So I
think what’s counterproductive is having there be just one way and that way is a
disability model.”
Michelle, a professor, and Alec each discussed how prejudice and assumptions can limit Autistic people’s potential. Michelle mused, “I wonder sometimes how maybe other populations might view [autism].” Alec said, “We need to see our differences and be understanding. You can’t go and say to someone that has autism that they’re not of value.” Theresa, a student, added a particular situation that makes her feel devalued, saying, “I feel like the focus on Autism Speaks on this campus is really counterproductive because it kind of perpetuates that idea that we’re these helpless beings that need to be cured and need so much help from the wonderful [non-Autistic] people.”

A specific area for potential support is that of engaging with non-Autistic peers. Participants on the whole agreed that empathy, willingness to learn, awareness of one’s own influence, and appreciation for diversity can go a long way. One parent, Maggie, said,

“I think probably one of the first things would be to start teaching early on, at the elementary level, actually, about the differences that we all have and what those differences look like, and how not to be afraid of what we don’t understand … I think a lot of my generation grew up not understanding and therefore fearing something that was different than us, and in order for our children to learn differently, we have to know and be able to teach them differently.”

Madeleine, a university staff member, seemed to echo Maggie’s sentiments, adding, “I think being aware of our own behaviors and how that can impact others is a really hard thing. It’s no big deal for me to change something, and if it can positively impact someone’s experience, it’s worth it for me to make that change. So I think for people to
learn more about what autism is and isn’t and pairing that with some self-awareness and that periphery of how what I’m doing in this environment may impact others.” These responses reflected priorities calling for cultural change to create greater tolerance and appreciation for neurodiversity.
DISCUSSION

Participants in the study offered a wide range of perspectives on successful college experiences for Autistic students and what supports might be necessary to make those experiences a reality. Despite a relatively small sample size, responses are often reflective of the same harmony and clashes that occur on a larger scale in dialogue surrounding autism.

An early example is the discord in responses about person-first language versus identity-first language. Amanda’s statement that she prefers person-first language because it is what she was taught to use reflects the emphasis on person-first language in most curricula surrounding disability. Meanwhile, five of the ten people interviewed, including both students on the spectrum, did not share this preference, and one parent preferred identity-first language. These different perspectives seem to illustrate an area in which what is being taught to those providing services to the Autistic community might not be in agreement with what the majority of the community is saying. Future research that investigates the possible existence of other such areas would likely be beneficial, as would research that delves deeper into the perspectives and experiences associated with these language preferences, as these perspectives and experiences are key aspects of culture as it relates to autism.

Another noteworthy theme that came up in the interviews was mention of autism as diversity rather than disability. Examples of attempts to deemphasize disability are frequently seen throughout society. Capitalization changes like “disAbility” and
neologisms such as “diffability” and “differently abled” are just a few oft-seen examples of these attempts. Additionally, arguments for person-first language base its importance in focusing on the person before the disability, even in a world where people frequently put other diversity-related adjectives before person-related nouns (brown-eyed girl, Asian man, etc.) seem to represent a similar urge to separate from disability in favor of “diversity.” Joan’s mention that college students did not seem to appreciate the therapy model of a social skills group she once set up may provide a clue as to the foundations of these ideas about rejecting disability. The idea that focusing on disability has to beget a therapy model seems to line up with the medical model of disability, which considers disability to be created by individual impairments or differences that should be corrected. However, many people, including many Autistic self-advocates, instead recognize disability is a branch of diversity (Shapiro, 1993). This viewpoint seems more in line with the social model of disability, a model which sees disability as a result of societal organization and barriers. Future research could delve deeper into these two models and consider how they relate to perceptions of autism and disability, particularly on college campuses. For example, is autism seen as a subset of overall disability culture? If not, in what ways might that affect Autistic culture?

One might hypothesize that those working more from the medical model of disability would have an increased affinity for “awareness” as opposed to the “acceptance” that seems to logically come with the social model. One of the students interviewed seemed to echo the experiences of many self-advocates in mentioning that “awareness” movement often discusses the difficulties that accompany autism and
interacting with Autistic people rather than discussing how to make the world more accessible to Autistic people. Meanwhile, “acceptance” as it relates to autism largely deals with removing societal barriers by accommodating the needs of Autistic people and appreciating their unique contributions. However, despite perhaps working from different models of disability, participants seemed to agree that “acceptance” was preferable to “awareness,” though only Theresa eschewed awareness entirely in favor of acceptance. Many respondents mentioned awareness as a step toward acceptance. A staff member mentioned during our conversation that she feels making people aware of the impact of their words and actions, coupled with spreading awareness about accessibility needs (for instance sensory needs in the case of Autistic people) can empower them to create an inclusive space. It seems that this kind of “awareness” is vastly different from the “1 in 68 people has autism” that often leads Autistic people to reject it. Understandings of awareness as a path to acceptance, and perhaps of different kinds of awareness, could be further explored in a future study by asking respondents to provide examples of awareness that promotes acceptance versus awareness that does not promote acceptance.

Nuances aside, promoting and honoring self-advocacy is logically a major component of acceptance. Historically, the voices of people without disabilities have often been at the forefront of advocacy movements, often to the detriment of those with disabilities (Shapiro, 1993). A large part of the disability right movement involves positioning people with disabilities at the forefront of issues that involve them. This idea is reflected in the Autistic Self Advocacy Network’s slogan “Nothing About Us Without Us.” Thus, perspectives on self-advocacy are important in understanding overall
perceptions of Autistic culture. Though qualitative findings are by nature not suited for generalization and my sample size is obviously not large enough to make major generalizations, ideas about self-advocacy seem to fit in well with the roles and experiences of the people in these groups in relation to autism. For instance, staff members, therapists, and professors usually have very goal-oriented positions in relation to Autistic students, which can explain their focus on self-advocacy as a means of getting needs met. Meanwhile, many parents probably rely on their children’s self-advocacy as a means of knowing and understanding them better, while Autistic people use their own self-advocacy to network and support themselves and one another. More research on perspectives about fostering self-advocacy will become increasingly important as the self-advocacy movement continues to progress.

Related to appreciation for self-advocacy, it seems noteworthy that the only two who talked about intentionally seeking out resources from people on the spectrum were on the spectrum themselves. This finding is consistent with the observations of Gelbar, Shefcyk, and Reichow (2015) that research and information surrounding autism often fails to incorporate the lived experiences of Autistic people. It is important to consider where the majority of people are getting their information about any marginalized group, because that often determines which voices are being heard. For instance, was most of the information gleaned by the professor who gets her information from “reputable websites – not things that looked fly-by-night” from Autistic people? Even if it were, much of the spectrum is still not represented enough in academia to contribute their voices to academic publications at all. The internet age has done wonders for the disability
community. People from all walks of life and with a variety of disabilities – including autism – are able to publish their experiences online. Many of these people would likely have not had access to so many resources and connections in the past, nor would they have been able to reach such a wide audience. Still, the focus on looking only at sources that would be considered academically reputable might prevent people from encountering the full range of Autistic voices. It is worth noting that the only two respondents who directly mentioned reading the work of self-advocates were the two students on the spectrum. When Autistic people are not at the forefront of creating and disseminating information about autism, people who are not on the spectrum run the risk of using assumptions as information, which can be harmful - and even abusive - to the Autistic community (Sequenzia, 2012). More future thought about ways to increase Autistic voices in literature about autism, particularly that to which the professionals and family members who will be helping them are exposed, seems crucial. Chown et al. (2017) have developed a framework for including Autistic people in “emancipatory” autism research, which should be incorporated into future endeavors.

Related to self-advocacy, making space for Autistic voices as mentioned by many participants as a key point in supporting students on the spectrum, as was access to administrative support and resources. Overall, it seems these responses can be summarized with the idea that open communication and exchange of dialogue about needs and possible solutions is paramount in terms of ensuring support, both overall and specifically as it pertains to Autistic college students. However, in a Catch-22 of sorts, the mere act of making space for Autistic voices will involve working to remove barriers
that may limit their communication with those who need to hear from them. Such barriers may include communication difficulties, access to opportunities, and uncertainty about whom to communicate their needs to in order to get help meeting them. Additionally, many people on the spectrum are also diverse in other areas such as race, gender, sexuality, and socioeconomic status. More work focusing on the overlap of these identities is important in making sure that the voices of all Autistic students are represented rather than simply those who already have fewer barriers against them.

Finally, as many interviewees mentioned, people on the spectrum are very different from one another with very different abilities and needs. There is, logically, no one-size-fits-all approach that will work for all students on the spectrum. Holistically supporting Autistic people, then, involves anticipating and meeting a wide range of needs and interests. More in-depth analyses of those needs and possible ways to support such a diverse group in a way that respects individuality and self-advocacy are needed.

This exploratory study set a foundation for future approaches to addressing the needs of Autistic students as well as needed resources to address their inclusion on college campuses. However, the small sample provides less generalizability and variability in responses than a larger sample size might. Additionally, participants had a wide range of understanding about autism and Autistic culture. While this range was helpful in illustrating the reality of diverse perspectives, different questions for different participants depending on their exposure to various topics could allow for more in-depth study. The Gobbo and Shmulsky (2014) model of focus groups could also be helpful in
understanding how different perspectives intertwine rather than simply studying them individually.

Themes of disability culture and models of disability frequently arose throughout the interviews. Future research should investigate how ideas regarding disability affect accessibility and services. Additionally, as the voices of self-advocates continue to spread and push for acceptance over awareness, more research about what acceptance entails in comparison to current practices will likely be important for professionals and other facets of society to understand what these changes will comprise. Additionally, results of this study could be investigated through the lens of a commonly-accepted sociological theory, such as social construction theory, to better understand the ways in which participants’ perspectives reflect and contribute to current zeitgeists. Overall, future research should incorporate the perspectives of Autistic people in a way that validates and empowers self-advocacy, as described by Chown et al. (2017).
WORKS CITED


Table 1

Study Participant Information

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role</th>
</tr>
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<tbody>
<tr>
<td>Alec</td>
<td>Autistic college student in his junior year of college</td>
</tr>
<tr>
<td>Theresa</td>
<td>Autistic college student in her junior year of college</td>
</tr>
<tr>
<td>Maggie</td>
<td>Parent of two students on the spectrum - one in high school, one in college</td>
</tr>
<tr>
<td>Jessica</td>
<td>Parent of one college student on the spectrum and one high school student who is not on the spectrum</td>
</tr>
<tr>
<td>Madeleine</td>
<td>University staff member who works under the umbrella of the Office of Diversity, Equity, and Inclusion</td>
</tr>
<tr>
<td>Abigail</td>
<td>University resident services staff member</td>
</tr>
<tr>
<td>Amelia</td>
<td>Professor of anthropology</td>
</tr>
<tr>
<td>Michelle</td>
<td>English professor</td>
</tr>
<tr>
<td>Amanda</td>
<td>School speech-language pathologist who works with children and young adults in grades K-12</td>
</tr>
<tr>
<td>Joan</td>
<td>Speech-language pathologist who practices through the university and teaches at the university</td>
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</tbody>
</table>
Table 2
Questions from the Interview

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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</thead>
<tbody>
<tr>
<td>Can you tell me about yourself?</td>
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<tr>
<td>What is your connection to autism today?</td>
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<tr>
<td>There is some discussion about the pros and cons of saying “person with autism,” known as person-first language, versus using identity-first language like “autistic person.” I’d like to use the language you’re most comfortable with for the rest of the study. Do you have a preference?</td>
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<tr>
<td>If I had never heard of autism before, how would you explain it to me?</td>
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<td>How would you define the term “self-advocate”?</td>
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<td>Why is self advocacy important?</td>
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<td>How can self-advocacy be supported?</td>
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<tr>
<td>When you picture successful inclusion for [autistic college students / college students with autism], what does that look like to you?</td>
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<tr>
<td>How can college students on the spectrum be supported to be better included in college?</td>
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<tr>
<td>What, specifically, would these supports look like?</td>
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<tr>
<td>What could be counterproductive to supporting college students on the spectrum?</td>
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<tr>
<td>In what ways are you currently involved in supporting inclusion for students on the spectrum in college or transitioning to college?</td>
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<tr>
<td>What can be done to prepare [non-autistic students / students without autism] to engage with their autistic peers with attitudes of acceptance and inclusion?</td>
<td></td>
</tr>
<tr>
<td>How can [autistic students / students with autism] be supported in engaging with their [non-autistic peers / peers who are not on the spectrum]?</td>
<td></td>
</tr>
<tr>
<td>How can professors promote acceptance and inclusion in their classrooms?</td>
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<tr>
<td>What are the sources you use for information about autism?</td>
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</tbody>
</table>
What is your understanding of the difference between autism awareness and autism acceptance?

We have reached the end of our scripted questions. Is there any other information you’d like to offer?