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## *Academic Ableism and Students with Intellectual/Developmental Disabilities Rethinking Self-Advocacy as an Anti-Ableist Practice*

Sean Kamperman

*Valparaiso University*

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### **Abstract**

*Per laws such as the Americans with Disabilities Act and the Family Educational Rights and Privacy Act, college students with intellectual/developmental disabilities (I/DD) in the United States are expected to be self-advocates and speak up for needed accommodations, regardless of diagnosis or condition. Students with I/DD in particular are frequently taught the dominant view of self-advocacy as a set of skills whereby they achieve self-determination. This view undersells the degree to which self-advocacy is a rhetorical enterprise, wherein students craft their speech to achieve immediate social purposes; and it elides the political history of self-advocacy in the U.S. and its ties to the adult self-advocacy movement. In light of these considerations, I seek to understand how ableism on college campuses gives shape to particular ideas about self-advocacy. Through five student interviews, I analyze how everyday talk about self-advocacy on a university campus is constructed through ableist discourses privileging mastery, concealment of bodily difference, and autonomy. Based on this analysis, I argue that it is necessary that educators reimagine self-advocacy as a collective responsibility engaging students, faculty, administrators, and staff in creating more accessible campus cultures, rather than as a hyper-individualized, self-directed pursuit of personal goals.*



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Over the past decade, important policy changes in the United States (US) have enabled a number of colleges and universities to open their doors to students with intellectual/developmental disabilities (I/DD). In particular, the Higher Education Opportunity Act (HEOA) of 2008 expanded access to financial aid for students with intellectual disabilities and their families and authorized the development of best practices for inclusive education programs through a model demonstration project. Consequently, the number of postsecondary education programs for students with I/DD has climbed from an estimated 13 in 2000 to 265 as of spring 2019 (“College Search,” n.d.; McEathron & Beuhring, 2011). With so many postsecondary options, a whole generation of youth with I/DD now have unprecedented access to higher education.

As standards for inclusive postsecondary education programs have evolved, teaching students self-advocacy skills has become an essential practice of many programs. To be designated a Transition and Postsecondary Program for Students with Intellectual Disabilities (TPSID) by Think College—the national coordinating center for the HEOA’s model demonstration project—a program must “provide a focus on academic enrichment; socialization; independent living skills, including self-advocacy skills; and integrated work experience and career skills that lead to gainful employment” (U.S. Department of Education, n.d.). Yet self-advocacy is a concept with multiple, sometimes contradictory meanings. While the adult self-advocacy movement champions a politicized approach to self-advocacy, many in special education see self-advocacy as a set of skills that is part of how an individual becomes self-determined (e.g. Wehmeyer, 1992; 1995; & 1998). Thus, what students learn about self-advocacy from TPSIDs can vary widely.

In this article, I explore interpretations of self-advocacy in higher education through the lens of institutional ableism. I do so by considering how five I/DD-identified college students enrolled at a U.S. institution of higher education talk about their experiences with self-advocacy. These students, referred to as Matt, John, Charles, Tyler, and Devin, were enrolled in a TPSID at a university in the Midwestern United States, referred to here as the ‘STEP UP’ program. The stories they told about self-advocacy link participation in the program to both positive outcomes—greater access to the curriculum and inclusion in campus life—and negative outcomes such as social ostracism. Using grounded rhetorical criticism, I consider how their experiences with self-advocacy were constructed through ableist discourses about mastery, in/visibility, and autonomy.

While studies of student self-advocacy and disclosure in higher education have grown increasingly numerous (Kerschbaum, Eisenman, & Jones, 2017), the postsecondary inclusive education literature sometimes leaves ableism out of such discussions. Freedman, Eisenman, Grigal, and Hart (2017), for instance, talk extensively about anti-disability stigma on college campuses, yet stop short of connecting stigma to ableism (pp. 294-296). Reframing stigma in terms of ableism is important, because it links problematic attitudes and beliefs to larger systems of oppression. Campbell (2001) has defined ableism as:

[a] network of beliefs, processes, and practices that produces a particular kind of self and body [...] that is projected as... perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human (p. 44).

Ableism, according to this definition, runs deeper than individual attitudes, permeating what inclusive educators Corbett and Slee (2000) refer to as schooling’s deep culture: “the hidden curriculum of fundamental value systems, rituals, and routines, initiations and acceptance that forms the fabric of daily life” (p. 140). Accordingly, studying ableism on college campuses requires

acknowledging how beliefs and practices that have apparently little to do with disability in fact make certain ways of moving and being unwelcome, even unimaginable, in academic spaces. For example, the belief that good students are those who participate vocally in class and exhibit independent, original thought is deeply ingrained in the culture of academia, with consequences for how students with I/DD are (or are not) included.

How does self-advocacy fit into this culture? Rather than assume self-advocacy is always good, I take a critical approach informed by Campbell (2009), Cowley and Bacon (2013), and other disability studies/ableism studies scholars, with the aim of thinking through some of the complications of self-advocacy efforts in institutions of higher education that have historically excluded people with I/DD. I begin by critiquing the popular educationalist interpretation of self-advocacy as a specialized skillset and facet of self-determination, an interpretation adopted by many TPSIDs. Next, I discuss how the culture of academia itself further delimits the rhetorical possibilities of self-advocacy, assigning student self-advocacy a highly conscribed place in the institutional hierarchy. I then turn to the student interviews to explore students' experiences of self-advocacy in this context. My argument is not that self-advocacy is harmful or undesirable, but that discourses surrounding student self-advocacy on college campuses can collude with ableism, as Campbell defines it, in unexpected and under-examined ways. In particular, my study, though limited in scope, suggests that everyday self-advocacy discourse on college campuses reflects contemporary higher education's hyper-individualistic culture, to the detriment not just of students with I/DD, but all students. As such, I argue for a shift from thinking of self-advocacy as a personal matter to thinking of it as a collective campus responsibility.

## **Background**

### *Individualistic Models of Self-Advocacy and Self-Determination*

Individualistic approaches to self-advocacy are encouraged both by the culture of academia and dominant special education theory and practice. The articulation of self-advocacy in the Think College curriculum, for instance, is heavily influenced by educationalist theories of self-determination (Grigal & Hart, 2010, p. 121). Wehmeyer (1992) originally defined self-determination as "the attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (p. 305). Wehmeyer thus conceives of self-advocacy as a set of communication skills whereby students express their choices or preferences, explain their needs, or stick up for their rights (see also Cunconan-Lahr & Brotherson, 1996; Lehr & Taylor, 1986). Over the years, the functional approach to self-determination and self-advocacy has produced a multitude of assessments and checklists enumerating the skills needed to be self-determined (Test, Fowler, Wood, Brewer, & Eddy, 2005; Wehmeyer, 1995).

Cowley and Bacon (2013) have noted many of the problems with hierarchical, functionalist approaches to self-determination in K-12 settings. First, such approaches assume students with I/DD lack self-determination and that I/DD professionals have the authority to decide when a student is or isn't exhibiting self-determined behaviors (p. 473-474). Second, historically, behaviors and attitudes recognized as self-determined by psychologists and other professionals have tended to reflect dominant cultural norms (cf Petersen, 2009). For instance, the ARC's Self-Determination Scale awards students points for behaviors such as going to concerts and movies, traits such as communicativeness and assertiveness ("I tell my friends if they are doing something I don't want to do;" "I tell others when I have new or different ideas or opinions") and for positive

attitudes (“I do not feel ashamed of any of my emotions”). Third, in the standards-based reform era, general population classrooms have been reluctant to integrate self-determination instruction into their curricula, resulting in students with disabilities spending less time in integrated classroom settings (p. 478). Particularly when students with disabilities are thought to require more time to develop self-determination than their nondisabled peers, heavily scaffolded, functionalist approaches to self-determination instruction can justify classroom segregation. Lastly, educationalist rhetorics of self-determination typically prioritize the needs and wants of the individual over social justice concerns. In effect, hegemonic definitions of self-advocacy as a path to and sub-skill of self-determination yoke self-advocacy to a teleological individualism, fashioning it as a tool for fulfilling personal needs. This marks a clear departure from the rhetoric of organizations such as the Autistic Self-Advocacy Network and Self-Advocates Becoming Empowered, who link self-advocacy to the larger political aspirations of the adult self-advocacy movement, thusly foregrounding self-advocacy’s sociopolitical (and collective) dimensions.

### *Ableism in Academia*

In the context of academia, these individualistic models of self-advocacy and self-determination can unintentionally reify the epistemic domination of disabled students by psychologists and other disability experts. Academia is highly stratified by mental ability (or perceptions thereof), with the most mentally ‘fit’ enjoying not only high status, but authority to define the reality of the mentally ‘unfit.’ This can be seen in the plethora of psychological constructs used to diagnose, classify, and manage mental disability. Stereotypes of people with I/DD as childlike are reinforced by folk theories of mental age, one of the key psychological constructs used to define I/DD in both medical and legal contexts. Gill (2015) writes that mental age “can actively discredit individual choice and perpetuate assumptions about incompetence, childhood, and necessity for protection by prioritizing medical authority at the expense of individual desire and epistemology” (p. 38). Similarly, Yergeau (2013 & 2017) describes how presumptions of communicative incompetence have historically provided justification for the unjust treatment of individuals with autism. Using concepts such as Theory of Mind, clinicians assume the power to define who is (or isn’t) “autistic enough” to make claims about autism, thus “denying the agency, rhetorical being, and personhood of autistic people” (2017, p. 32). While colleges and universities are intellectually diverse places that harbor multiple views on disability, academic discourse by and large has served to objectify disability and disempower disabled subjects (Dolmage, 2017; Linton, 1998; Price, 2011).

The circulation of these discourses on college campuses reinforces the idea that I/DDs are problems to be solved rather than diverse ways of being. When students speak up, they therefore do so from a place of limited power and credibility. To complicate matters further, students may be hesitant to speak up or reach out for help at all for fear of appearing incompetent. In a myriad of ways, colleges and universities send the message that struggling is not normal or acceptable, in spite of efforts at many institutions to normalize psychological distress. The notion that students are expected to evolve, not regress; to leave campus as smarter, more capable humans, is so fundamental to the meritocratic mission of higher education, it is nearly impossible to conceive of failure in such a context as anything but negative. Aligning his critique of academic discourse with Halberstam’s (2011) “queer art of failure,” Dolmage (2014) identifies academic narratives that celebrate success and derogate failure explicitly with ableism and heteronormativity, arguing that a truly positive embrace of disability requires a reorientation toward failure altogether (p. 158).

Moreover, academia's meritocratic mission results in policies that can make campus life difficult for people with mental disabilities. Under existing laws, standard course accommodations such as extra time on tests are easier to obtain than the substantial course modifications some students with I/DD require (Thomas, 2000). While the legal justification for such policies is complex, there is a widely held assumption that course modifications are unfair and that they pose a threat to academic rigor. Blanket attendance and leave of absence policies that ignore individual differences can also disadvantage students, faculty, and staff with disabilities (Price & Kerschbaum, 2017).

These beliefs and institutional norms delimit the possibilities of student self-advocacy. To achieve recognition of their needs, students with I/DD are expected to speak and act in certain ways: to be assertive, articulate, yet deferential, and to operate within the standard system of accommodations. While this style of communication certainly has its uses, it is important to recognize a wider range of affective and rhetorical strategies as valid for the purposes of self-advocacy. Otherwise, self-advocacy can become a normalizing discourse that fails to achieve significant institutional change.

## Methods

### *Participants and Research Site*

I interviewed Matt, John, Charles, Tyler, and Devin over the 2017-2018 academic year. My interview questions focused on the students' perceptions of self-advocacy. Participation was open to any student enrolled in the STEP UP program. Matt, John, Charles, Tyler, and Devin each volunteered to participate after I met with them individually to introduce myself and explain the goals of the study. Matt was auditing a course I instructed at the time I interviewed him, so I took extra precautions to ensure he understood his participation was voluntary and would not affect his performance in the class. All five participants were first-year students at the time of the study.

The STEP UP program is a well-regarded TPSID. Located at a university in the Midwestern United States, STEP UP offers a two- or four-year program where students take both standard courses with the general student population and specialized courses offered only to program participants. To be admitted, students must have a diagnosis of I/DD and demonstrated ability to succeed in a structured school environment. Participants are given the opportunity to hold multiple internships throughout their time in the program and to live on campus. Self-advocacy is integrated into the curriculum in many ways, including skill-based instruction and student-led Person-Centered Planning meetings. Upon graduating, students earn a workforce development certificate.

All of my participants were cis men. Four (Matt, John, Tyler, and Devin) were White, and one (Charles) was Black. I attempted to recruit a more diverse sample, but was constrained in doing so by time restrictions and the demographics of the STEP UP program (student cohorts tend to be small and predominantly male).<sup>1</sup> Three female-presenting students expressed some interest in the project but ultimately declined to participate. As such, further research is needed to explore differences in how multiply-marginalized students with I/DD labels in TPSID programs experience self-advocacy. While I did not require participants to disclose their diagnoses, based

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<sup>1</sup> The TPSID student population in the U.S. skews male. In 2018, 62% of students enrolled in TPSIDs were male, while 38% were female (Grigal, Hart, Smith, Papay, & Domin, 2019).

on information gathered from those who voluntarily disclosed, participants had disability diagnoses including ID, ADHD, and autism. In my conversations with them, none of the students I interviewed preferred disability-first and identity-first language.<sup>2</sup>

### *Research Design*

The goal of the interviews, which ran 40 to 60 minutes each, was to explore participant conceptualizations of self-advocacy's role in activities related to campus life (e.g., traveling to and from campus, participating in class, joining a student organization, making friends, etc.). Anticipating that some participants might struggle making connections between abstract terms such as self-advocacy and self-determination and concrete activities, I adapted the language of my interview protocol as needed, replacing references to self-advocacy with phrases such as "stand up for yourself" and "ask for help." (The full interview protocol can be viewed in Appendix A.) Overall, the interviews were fairly unstructured. Students were informed that the study was about self-advocacy and invited to share their own interpretations of the term ("What does self-advocacy mean to you?"). Four of the five students were familiar with the term and gave their own definitions, while one was not.

Because of the limited data collected for this study, these findings should not be interpreted as representative of the self-advocacy experiences of college students with I/DD. Further, because studies involving participants with I/DD invariably involve power differentials (Williams, 1999 & 2011), my role as investigator must be examined. I attempted to downplay my authority, validating participant responses and striking a friendly, invitational tone. Still, as a nondisabled, white, cis man, a researcher, and a university employee, I occupied a position of power that inevitably influenced the students' responses to my questions. Through demanding attention to the ways in which messages are crafted for particular audiences, rhetorical analysis can help researchers attend to such power issues. I analyze Matt, John, Charles, Tyler, and Devin's words not as transparent accounts of 'true' events or unvarnished beliefs, but as performed speech for a particular audience: or what Bamberg (1997) calls "positionings," attempts to achieve immediate social purposes through narrating the past (p. 335). By examining my own part in these interactions, my analysis seeks to clarify my role, as audience and as speaker, in conditioning participant responses.

Using constructivist grounded coding methods (Charmaz, 2008; Clarke, 2005; Glaser & Strauss, 1967), I identified three themes in the data: 'self-mastery/mastery over the future,' 'negotiating in/visibility of bodily difference,' and 'ability to function autonomously' (hereafter shortened to 'mastery,' 'in/visibility,' and 'autonomy'). In containing such themes, talk about self-advocacy can be analyzed in relation to ableist narratives that normalize certain ways of thinking and being (see Table 1). To arrive at these themes, I used axial coding (Gasson, 2004), a process where the researcher groups codes along continua of similarity and difference. Accordingly, my analysis moved from descriptive, action-oriented coding toward the development of progressively more analytic code categories that were influenced by my reading of the disability studies literature. Unlike classic grounded analysis, constructivist grounded analysis encourages applying

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<sup>2</sup> While many members of the disability rights movement embrace a disability-first approach to disability identity, many members of the adult self-advocacy movement have evinced greater ambivalence toward claiming disability, questioning its liberatory potential. See Carey (2013) and Brown (2014) for nuanced discussions of labeling and identity.

theories from other disciplines, so long as the researcher ascertains their fit through constant comparison of data, code, and category (Charmaz, 2008).

**Table 1**  
Ableist Institutional Discourses: Codes and Definitions

<i>Category</i>	<i>Sample codes</i>	<i>Example from data</i>
<p><b>Mastery</b></p> <p><i>Definition:</i> Discourse that naturalizes perfection, improvement over time</p>	<p>Talking about goals; talking about the future; identifying weaknesses; talk about overcoming disability</p>	<p><i>John:</i> Like I’ve grown so much, I had to do therapy, you know and all that, work with, uh, different teachers, and, um, learning how I could overcome autism...</p>
<p><b>In/visibility</b></p> <p><i>Definition:</i> Discourse about revealing/concealing embodied difference</p>	<p>Explaining need for accommodation; defining disclosure; blending in</p>	<p><i>Sean:</i> And so in general, would you say you prefer to... sort of keep that [disability] to yourself?  <i>Tyler:</i> Yeah... because of... past experiences where it’s backfired.  <i>Sean:</i> Can you think of a situation where you might... be more open to sharing about that?  <i>Tyler:</i> Not at the moment. [laughs]</p>
<p><b>Autonomy</b></p> <p><i>Definition:</i> Discourse that valorizes independence over interdependence</p>	<p>Defining independence; talking about dealing with an academic struggle independently</p>	<p><i>Sean:</i> Do you have to be more independent [now that you’re in college]?  <i>Matt:</i> Yes  <i>Sean:</i> Okay. Can you tell me a little more about that?  <i>Matt:</i> Being independent is doing things the right way by yourself... I try that, but it’s a little hard for me...  <i>Sean:</i> [W]hat’s hard?  <i>Matt:</i> The notes... Writing neatly.</p>

**Findings & Analysis**

*Mastery*

The students I spoke with revealed a tendency to position self-advocacy as a skill one gets better at over time and a means of improving one’s self (Table 1). John said his “advocating” had “definitely improved” since joining the STEP UP program: “I’ve definitely felt a lot more comfortable with sharing... what I’m feeling and what I need help with.” He described “going

through” self-advocacy as necessary for realizing his dream of becoming a professional artist. Devin defined self-advocacy as “goals,” “what you try to achieve.” Other students spoke positively about the psychological benefits of skills associated with self-advocacy, such as assertiveness. Charles, who shared stories about being harassed on campus, affirmed that these experiences made him more “confident... for standin’ up for myself.” Tyler, who defined self-advocacy as “standing up for myself,” expressed confidence in his self-advocacy skills, and spoke about consciously modeling these behaviors for other STEP UP students. While some of the students talked about self-advocacy’s drawbacks or told stories of past failures, in general, self-advocacy figured in these interviews as a mechanism of change; a tool for exploring interests, accomplishing goals, solving problems, and overcoming adversity; and an agent of personal growth.

Self-advocacy’s entanglement in personal growth narratives speaks to the influence of discourses that celebrate mastery and derogate failure on college campuses. My participants’ accounts revealed two dimensions of mastery discourses: a temporal and a spatial. Temporally, mastery narratives posit more abled futures as better futures. Even the stories I heard about spontaneous acts of self-advocacy—unplanned, in-the-moment—were wrapped up in the students’ attempts to present themselves as better than they used to be. Tyler, for instance, simultaneously played up self-advocacy’s reflexive qualities (defining it as “standing up for myself in any situation whatsoever”) while explaining that standing up to bullies at school and at work taught him self-reliance. His account thus enfolds individual stories of self-advocacy into a developmental arc terminating at a superior, more able version of himself.

Often, such narratives involve distancing from one’s disability through overcoming. While Tyler talked about his diagnoses as a part of his everyday life (and thus, his present), John talked about overcoming his disability and leaving it in the past. Kafer (2013) argues that these developmental logics are predicated on the ableist idea that we all desire nondisabled futures (p. 3). When I asked John if he identified as disabled, he replied that he was diagnosed with autism as a kid, but that he “overcame” it through spirituality and interacting with others. “I’ve learned a lot from it, and I’ve learned how to grow out of it.” When I asked him to elaborate, he said

I grew out of it because I don’t see myself... bein shy anymore... all of my, you know, learning disabilities, like... I’ve faced a lot of em and I know what I have and what I don’t have and like, what I can do and what I cannot do... I mean reading’s still a huge... problem, and writing, and y’know math... but y’know... I’m fightin it... that’s all I can do from autism and ADHD, ya just gotta fight it.

In addition to positioning his autism in the past, John deploys the oppositional, masculinist rhetoric of “fighting” disability to disidentify from I/DD. He describes self-advocacy—more specifically, speaking up when he needs help—as a crucial life skill he’s used, paradoxically, to overcome disability. Schalk (2016) points out that inspirational narratives such as these, when told by people with disabilities, can have positive, community-building and anti-ableist valences. Yet given his audience (me, a nondisabled interlocutor and perceived authority figure), John’s effort to temporally distance himself from his disability by locating it in the past can plausibly be read as an effort to appear more competent by claiming a more perfect, less disabled self. Unwittingly, some of my contributions to this conversation likely encouraged this self-presentation. John sounded embarrassed when discussing his struggles with reading and writing (“[R]eading’s my... my, uh... my weakness[ ]”). Sensing this, I tried to offer him some encouragement: “But you’re very good at talking.” He agreed. “Yeah... I mean I could talk all day... Like I’d rather talk than write a paper.” My instinctual reflex to turn a conversation about John’s limitations into a



conversation about his strengths reveals a cultural discomfort with failure. John and I share an understanding that in hyper-competitive academic environments, presenting as capable entails social rewards, while dwelling on limitations does not.

The spatial dimension of mastery refers to talk that positions self-advocacy as a tool for perfecting one's embodiment in a given space. Here, the emphasis is less on projecting a perfected or improved future self than on mastering one's body in relation to one's immediate surroundings. Educational psychologists sometimes discuss such mastery in terms of "self-regulation," defined by Whitman (1990) (quoted in Wehmeyer, 1995) as "a complex response system that enables individuals to examine their environments to make decisions about how to act, to act, to evaluate the desirability of the outcomes of the action, and to revise their plans as necessary" (p. 373; see also Wehmeyer, 1995, p. 19). Demonstrating his uptake of such concepts, Tyler used the term "cognitively aware" to distinguish between students who behave properly in public and students who act up, suggesting that cognitive awareness (self-regulation) is part of effective self-advocacy. When I asked him to elaborate, he explained that cognitively aware people "pay attention to what they're doing" and "know that there's a certain etiquette in college, and they follow that." The rhetoric of behavioral science—specifically, educationalist rhetoric of self-determination—gives Tyler a language for constructing good behavior as normal and rude behavior as psychologically deviant. This speaks to the dominance of the rationalist, managerialistic idea that 'abnormal' behavior is a problem to be fixed, an idea found in both the psychological literature and the ways students with I/DD are taught (intentionally or no) to see themselves.

A downside of self-regulation rhetoric is that it can lead students to view their behavioral and linguistic capacities as deficient. Devin, for instance, seemed to find fault with his tendency to exaggerate and the limits of his vocabulary. Despite doing his best to "sound professional," he said he "sound[s] like a kid sometimes," because he has difficulty pronouncing certain sounds. The fact that people who identify or are identified as having I/DD are frequently misrecognized as childlike, a longstanding prejudice embodied in the idea of cognitive age, likely contributes to Devin's insecurities. As Kafer (2013) notes, invoking Halberstam (2011), even stories about the future that do not focus on disability tend to "presume a linear development from a dependent childhood to an independent adulthood defined by marriage and reproduction" (p. 35). Devin's concern about not sounding adult enough thus connects to ableist cultural representations of age and development. By teaching students that mastering language holds the key to a desirable future, postsecondary educators (particularly in fields such as rhetoric) no doubt contribute to these concerns.

### *In/visibility*

The theme of 'in/visibility' refers to talking about the revealing and concealing of bodily difference (Table 1). Disclosure was a frequent topic of my conversations with the students, many of whom expressed ambivalence about revealing their disability status to their nondisabled peers and professors. Tyler said that, in general, he preferred to keep his disability status to himself, "because of past experiences" where disclosing it "has backfired." When I asked him if he could think of a situation where he might be more open to sharing his disability status, he replied wryly, "not at the moment... because of how many times it's backfired." Similarly, John talked about having to overcome his fear of asking for help in class. "[S]ay I ask a question and people laugh at me, cause it's like a funny question, but it's like actually a serious question, and then I feel ashamed." Charles told a story about an instructor who took longer to return his grades once they learned about his disability. Understandably, experiences like these make some students with I/DD

hesitant to advocate for their needs. Unfortunately, in predominantly nondisabled, historically exclusionary spaces, when access depends on self-advocacy, students' silence can reaffirm the status of the college classroom as a space devoid of intellectual disability, perpetuating cycles of inaccessibility.

Chouinard (1997) writes that the presumption of able-bodiedness marginalizes disability—in particular 'invisible' disabilities (p. 380). If one does not outwardly appear to be disabled, it is generally assumed they are not. As Campbell (2009) explains, “[a]bleist normativity results in compulsive passing, wherein there is a failure to ask about difference, to imagine human beingness differently” (p. 4). The invisibilization of disability in contemporary social space has its roots not just in social mores, but in law. Carey (2013) has traced contemporary attitudes toward passing to early 20<sup>th</sup>-century eugenicist laws restricting the rights of people categorized as ‘feebleminded’ to appear in public spaces. Today, laws that protect student privacy, such as the Family Educational Rights and Privacy Act (FERPA), can inadvertently reinforce the cultural regimes of silence and passing that have historically surrounded mental disability in the United States. By treating disability as a matter of private record, FERPA affords students some protection from involuntary disclosure. Yet it also has the unintended consequence of transferring the rhetorical burden of self-advocacy to students, who may be understandably reluctant to disclose when doing so could entail a loss of social status.

Compulsive passing reifies the notion that disclosure falls within the individual's control, underselling the degree to which intellectual/learning/developmental disabilities are not “invisible” but “apparitional” (Price, 2011; p. 18). By using the term “apparitional,” Price explains that mental disabilities are sometimes perceptible, sometimes not. Students with I/DD will thus have varying experiences of control over whether and when they disclose. For instance, I/DD can be marked not only by individual characteristics (anatomical features, behaviors), but by the visibility of particular forms of support. On most campuses, in order to receive accommodations, students with disabilities must register with the campus office of disability services. Once registered, students can meet with counsellors to arrange course accommodations such as note-takers and extra time on tests. Instructors are legally prohibited under the Americans with Disabilities Act (ADA) from inquiring about the reason for an accommodation request received through disability services. This too nominally affords the student some degree of privacy. While TPSID students are eligible for these same services, and thus have means of receiving accommodations without the knowledge of their classmates, some forms of support can reveal the student's disability status to classmates. Many TPSIDs, for instance, use education coaches or peer mentors who accompany the students to their general education classes to help with note-taking and other in-class activities. In smaller classes, the presence of an education coach can essentially ‘out’ the TPSID student.

It is true that by virtue of their embodiment, some students are able to confine disclosure to the realm of discourse (and, by extension, ‘control’ disability as an object of speech). Tyler and John, as mentioned above, both talked about passing, or “blending.” For students who cannot pass so easily, other rhetorical strategies become salient. Matt, for instance, who has a noticeable speech impediment, seemed taciturn in comparison to the other students I spoke with. If one's speaking has the potential to out them, not speaking up can be a valid rhetorical tactic. Another consideration is that some students' behaviors are coded as abnormal because of their race.

Charles, who is Black, shared a story about a time he was approached by campus security and accused of being disruptive:

They asked me did I have any... loud noise... playin from my phone. I said 'no,' ... and they said, uh, 'we, we just checkin. We just wanted to make sure you not... [disruptin] the community, because everybody has they own thoughts, like... you see people like with they headphones in... yelling [?], disturbin the community.' I said 'hey officer, um, security, I didn't have my phone out, I was just only textin my mom, and then, and that was it. I didn't have no, I didn't have the volume up, and I was not being destructive [?].'

Next, the officers asked Charles to show them his campus identification card:

[T]hey come up to me cause you supposed to have your [school] ID... everywhere you go... So both of them asked me for my ID. I didn't do anything wrong, I wasn't disrupting [?] the peace... I didn't pull it out... and they went away... I didn't take my ID out... because... anybody can go in the Union, like students or... guests... I didn't do anything wrong, I was just mindin my own business, waitin for a friend...

Charles is well aware of his right to be on campus free of harassment by security. Yet in his story, his status as a student is called into question on account of his supposedly disruptive behavior. It is apparent Charles's experience as a young Black man makes him feel uncomfortable around campus security guards, whom he believes single him out because of his race. His story is thus a reminder that because ableism and racism are co-constitutive, students of color may find it more difficult to 'pass' than their white peers when their behaviors (in Charles's case, hyperactivity) mark them as different (Annamma, Connor, and Ferri, 2013; Erevelles, 2011). It is also a reminder that students with I/DD, who are disproportionately victims of violence, may justifiably feel unsafe disclosing their disabilities in certain spaces, especially given the historically fraught relationship between people with disabilities and law enforcement (Carey, 2013).

### *Autonomy*

Ableist autonomy discourses are those that promote the idea that independence is better than interdependence (Table 1). On college campuses, educationalist and even rights-based rhetorics can imply that self-advocacy is about learning how to fend for one's self. The students I spoke with reflected this understanding in their responses to my question, "What is self-advocacy to you?" Devin defined self-advocacy explicitly in relation to "independent stuff," such as "getting on the bus on time," "getting up in the morning," "feeding yourself," "driving," and "getting a job." Tyler defined it as "standing up for myself in any situation whatsoever." John identified self-advocacy as the best independent living skill he'd learned. The differences between these descriptions of self-advocacy and official definitions suggest that, in everyday use, the term self-advocacy means more than speaking up on one's own behalf; it connotes a way of life, a stance toward life's challenges grounded in self-reliance. In the STEP UP program, first-year students learn about self-advocacy in their required independent living course, which could explain why the students responded in this way.

Far from implying that some degree of independence is not a worthy aspiration, my purpose is to point out some of the ways inclusive understandings of independence intersect with neoliberal discourses that celebrate radical individualism, discourses that are commonplace on college campuses. This requires attention to the ways institutions of higher education discourage *interdependence*. By attaching notions of scholastic merit to individual accomplishments, academia creates an environment where students are expected to distinguish themselves as

individuals while abiding by a standard set of rules. Proponents of the status quo in higher education defend academia's individualistic culture by appealing to the idea of a 'level playing field,' whereby disabled students are supposedly made equal with their nondisabled classmates through the standard system of accommodations. Any form of interdependence or collaboration that falls outside this standard system is penalized, while use of unauthorized assistive technologies (such as using a laptop during a test) is considered cheating. Students must rely on a standardized set of aids to accomplish their work: reading lists, writing implements, computers, libraries, etcetera.

Academia's rigid rubrics for (de)legitimizing collaboration manifested in the students' accounts in divergent ways. Some students, like Matt and Charles, expressed frustration at program policies that inadvertently made certain forms of support unobtainable. Charles vented at length about his education coach's refusal to help him with his homework (a responsibility technically outside the scope of the education coach's role). He also described an instance in which social coaches, student volunteers assigned to accompany STEP UP students on social outings, failed to stand up for him in a confrontation with a stranger. Other students talked of eschewing help altogether. Tyler's stories in particular tended to highlight his agency as a lone actor, focusing on his use of reason to navigate conflict and stick up for himself. He evinced pride in being "low maintenance." "They [the staff] know that I'm gonna stand up for myself if need be." When I asked him what he meant by that, he explained

I'm so... aware of my issues and able to take care of myself... so much better than a lot of the other kids in the program... at the moment... they [the staff] were like 'oh. We won't have to do anything really for this... guy... Maybe help him with the buses... and health insurance, but that's about it.

As Tyler spoke, I remembered my own reluctance to seek help for academic and emotional concerns when I was a college student. Tyler's response shows how in competitive academic environments, self-advocacy can easily be conflated with self-reliance. Cis male students in particular may be apt to misrecognize reliance on others—interdependence—as a sign of weakness.

In addition to their role in discouraging help-seeking behaviors, ableist autonomy discourses naturalize particular human-machine collaborations while denaturalizing others. This was evident in my interview with Matt, whose speech impediment demands (opens up) an explicitly interdependent approach to technology and face-to-face interaction. In order to understand him, I had to ask him to repeat himself often. He would occasionally help me by breaking his response into parts, or by tapping along with the beat of each syllable, using his finger like a metronome. I knew from class that Matt also had a smartphone app called MPiStutter, which visualizes his rate of speech using different colors, cueing him to slow down when necessary. However, despite our both being aware of the app, he didn't use it until I specifically asked him about it roughly two-thirds of the way through the interview. Even then, my request was for him to demonstrate how it worked, not to use it for assistance. Instead of using the app, he appeared to put his energies into maintaining eye contact.

Matt's attempts to maintain eye contact and speak face-to-face without the help of the MPiStutter app speak to the hegemony of able-bodied interactional norms in academic spaces. Certainly, MPiStutter has practical limitations—it makes multitasking difficult and eye contact nearly impossible. Under the rubric of self-determination, it might also be argued that Matt's

choice to maintain eye contact was self-determined and therefore unproblematic. I would argue, however, that Matt's conspicuous neglect of his communication aid while talking to me, his instructor, testifies to more than technical shortcomings, pointing to a larger, ableist culture of communication underwriting face-to-face interaction in academia. Though I took pains to ensure he understood his participation was voluntary, as his instructor, I occupied a position of power that no doubt influenced Matt's communication tactics. I did not want to pressure Matt into using his app, because I did not want him to feel that his communication was somehow inadequate or that the interaction was 'failing.' Examining the assumptions underlying this decision, I realize I prioritized a semblance of normality over communication. Stuck in an ableist communication paradigm, according to which meaning and meaning-making rests primarily on verbal abilities and eye contact, our interaction neither resulted in efficient communication nor validation of Matt's disability status. This interaction demonstrates how the practices governing technology use in academia intersect with communicative norms and myths of bodily autonomy to stigmatize assistive technologies like the MPiStutter app.

### **Conclusion**

These accounts of self-advocacy highlight its role as a tool for self-improvement, negotiating disclosure, and achieving independence. While Matt, John, Charles, Tyler, and Devin are not representative of all students with I/DD, their accounts speak to widespread self-advocacy struggles, such as choosing when and whether to disclose; how to represent one's disability; how to obtain needed supports through accommodation centers when faculty have limited knowledge of disability; and how to balance the need for support with the desire to blend in with peers. Some of the students I spoke with, namely Charles, seemed comfortable asking for help, while others did not. In effect, the individualistic approach to self-advocacy espoused by many TPSIDs expects students to ask for help in environments that generally do not reward such behavior and conceives of self-advocacy primarily as a way of achieving one's self-determined goals, as opposed to a social process involving the student in rhetorically rich interactions between people with sometimes conflicting goals. While the self-advocacy of students with I/DD on college campuses has the potential to reveal injustices and disrupt normative approaches to higher education, perhaps in fundamental ways, depoliticized, individualist approaches to self-advocacy can only do so much.

Inspired by Cowley and Bacon's call for a critical context-based approach to self-determination, I advocate for an anti-ableist approach to self-advocacy instruction that sees self-advocacy talk and practice as fully situated in social structures. In contrast to psychological definitions of SD that construct self-determination "as a personal matter relegated to an individual's body: a dispositional character trait with little attention paid to context and social process" (p. 469), Cowley and Bacon argue that self-determination should be seen as a "social phenomenon" (p. 479) and "theorized as an emancipatory process" (p. 480). I would add that, to realize self-advocacy's political potential, self-determination and self-advocacy must also be seen as rhetorical phenomena. If self-determination is understood to manifest differently across social and geographic contexts, we should not be surprised when students are vocal in one place and quiet in the next. To view quietness as a lack of willfulness is to accept a rhetorically impoverished picture of self-advocacy. None of this is to deny that 'skills' like assertiveness can be learned and applied across contexts; rather, it is to affirm the importance of a rhetorically valid self-advocacy curriculum that values multiple communication modes and tactics.

Rhetorically valid, anti-ableist approaches to self-advocacy have the potential to make higher education more inclusive, but only if they are embraced by a majority of the campus community, not just those with disabilities. By keeping what Konrad (2018) calls “the everyday rhetorical labor of disability” (p. 127) largely out of view of nondisabled students and staff, the separate accommodations system turns access into a professional rather than political concern. Similarly, by designating TPSIDs the ‘proper place’ for students with I/DD, colleges and universities may limit opportunities for disability pride and inclusion. Fortunately, many programs—such as Syracuse University’s InclusiveU, an initiative of the Lawrence B. Taishoff Center for Inclusive Education—have demonstrated how TPSIDs can work in tandem with campus-based disability rights organizations to advocate for broader inclusion. At Syracuse, TPSID staff help faculty adapt their courses for learners with I/DD. Such efforts could be easily replicated at other institutions.

Though limited, this study suggests several other areas where disabled and nondisabled campus community members can work together to enact meaningful change.

1. By disclosing their own struggles and encouraging students to do the same, instructors can work against campus rhetorics that derogate failure, decentering competence as the assumed norm and reminding students that learning is a process. Going a step further, instructors can challenge students to reflect on how success and failure are themselves socially constructed. This could have the effect of depersonalizing failure and reducing the stigma attached to it.
2. Instructors can embrace universal design for learning, an educational framework that supports flexible learning environments to accommodate a variety of learning differences (see Dolmage, 2015). Far from obviating the need for self-advocacy, universal design *normalizes* self-advocacy, since it assumes from the start that all learners have different needs, and that creating an environment that can meet those needs requires ongoing input from all members of the class.
3. Groups and individuals on campus who are committed to anti-racist action can continue educating their communities on how racialized notions of ability put disabled students of color and other multiply marginalized groups at greater risk of segregation, violence, and marginalization.
4. Instructors can partner with campus technology specialists to naturalize assistive technologies. This can be accomplished in part through *denaturalizing* ideas that it is normal and therefore natural to use certain technologies and not others.
5. Instructors, students, and administrators can work together to develop alternatives to assessment practices that reward hegemonic ways of thinking, speaking, or writing while punishing others. Models such as Inoue’s (2019) labor-based grading contract system, which grades students based only on the labor they complete toward achieving defined learning objectives, could work well in inclusive learning environments.

6. Finally, student organizations, scholarly communities, and TPSIDs can work together across campuses to include students with I/DD in disability rights/pride movements. By establishing cultures of anti-ableist self-advocacy on their own campuses, and continuing and encouraging the exceptional efforts already underway at other institutions, these groups can spark the broader cultural change needed to make student self-advocacy a truly transformative, anti-ableist practice.

## **Appendix A**

### **Interview Protocol**

- 1) Where are you from?
- 2) How long have you been in the STEP UP program?  
Proceed with these factual “warm-up” questions until participant is comfortable.
- 3) Tell me about a time you asserted/stood up for yourself.
  - a. If they have examples: have them recount the episode. Ask for as many details as possible (e.g., Who was there? What was happening?).  
Follow up by asking whether they feel they were successful. If no: why not?  
Take this question to saturation—ask them to recount as many episodes as possible.
  - b. If no: move on to next question.
- 4) Tell me about a time you asked for help.
  - a. If they have examples: have them recount specific episodes. Ask for as many details as possible (e.g., Who was there? What was happening?).  
Take this question to saturation.
  - b. If no: move on to next question.
- 5) How do your conversation skills help you achieve your goals?
- 6) Do you find you have to talk to people in different ways, depending on the situation, to persuade them or get them to understand you? How so?
- 7) Do others help you assert/stand up for yourself? Who are they? Can you tell me about a time someone helped you assert/stand up for yourself?
- 8) Tell me a little about how you like to communicate.  
If necessary, clarify with follow-up questions. E.g., “How do you let people know you’re upset, happy, that you need something, etc.?”
- 9) Is there anything else you’d like to tell me related to the things we’ve talked about today?

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### **Author**

Sean Kamperman is an Assistant Professor of English at Valparaiso University. His research examines rhetorical issues such as ethos, credibility, and communicative competence in relation to disability rights, public deliberation, and health communication. His work has appeared in *Disability Studies Quarterly* and the *Gayle Morris Sweetland Digital Rhetoric Collaborative*. He can be contacted at [sean.kamperman@valpo.edu](mailto:sean.kamperman@valpo.edu).

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