"Moving quietly through the door of opportunity": Perspectives of College Students who Type to Communicate

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“Moving quietly through the door of opportunity”: Perspectives of College Students who Type to Communicate

Christine E. Ashby and Julie Causton-Theoharis
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Colleges and universities across the United States are becoming increasingly diverse. That increased diversity includes students who do not use speech as their primary means of expression. This qualitative study focuses on the experiences and challenges of higher education for individuals with autism who type to communicate using a method known as facilitated communication. This article focuses on the perspectives of these individuals as they make sense of their inclusion in and, at times, exclusion from higher education, particularly their academic and social access. In addition, the findings of this research indicate that while there are structural and classroom supports that are helpful for individuals who type to communicate, their participation and meaningful inclusion is also incumbent on attitudinal factors and how receptive faculty and staff are to the students’ method of communication. While there is still much work to be done in the area of higher education for individuals with more complex needs, this study highlights the promise of higher education for this new population of students.

Leo¹, a student with autism who types to communicate² through a method known as facilitated communication and who is enrolled in an inclusive higher education program at a private northeastern university, shared the following about his hopes. “I only have two more years to complete my studies. I wish I had more time. Then I would be a doctor of philosophy. Please take me seriously here. I am smarter than even I know right now.” Leo had typed this statement to share with his peers in his graduate class on inclusive education law and legal advocacy for inclusive education. Another student who types to communicate, Diana, gave the following introduction to a speech on inclusive higher education and shared a little about her dreams for the future, stating:

I am a graduate student at Starwood University³, seeking my master’s degree in Disability Studies. I have been told that I currently hold the distinct privilege of being the only non-verbal graduate student in the United States. I know this is a temporary place of honor with the hopes of those who use a form of augmentative communication will follow soon all over the world.

The following qualitative study focuses on the experiences, perspectives, and challenges of higher education for individuals, like Leo and Diana, who type to communicate.
Diana’s dream of students with autism who are also nonverbal attending college and university programs was unheard of until recently. Isolated facilitated communication users began attending college in the mid- to late-1990s, but now, there are a growing number of individuals (we estimate 20 to 25) with disabilities who type to communicate accessing higher education programs nationally. Some of these individuals are non-matriculated students, enrolled in non-degree-granting programs housed on college campuses. However, some individuals, like Diana, have been accepted into degree-granting programs as fully matriculated students, completing their coursework using alternative communication methods. All of the students in the present study type to communicate. To set the stage for this research, we first review relevant literature on the prevalence of college students with disabilities and introduce the concept of typing to communicate and understandings of competence.

LITERATURE

College Students with Disabilities

Participation in some form of postsecondary education is on the rise for students with disabilities. According to a 2006 report, 11.3% of college students identify as disabled (National Center for Education Statistics [NCES], 2010). This was up from 6% about ten years prior (Henderson, 2001). In 2000, it was estimated that 37% of students with disabilities entered postsecondary programs (Wittenburg, Fishman, Golden, & Allen, 2000) with far fewer students considered to have significant disabilities attending college. Recent data indicate that approximately 46% of students with disabilities are entering postsecondary educational programs (NCES, 2010). The latest figures from NCES report student enrollment data disaggregated by disability category. In 2005, 28.1% of students with the label “intellectual disability” enrolled in postsecondary education. The newest data on students with autism are harder to parse out, as the NCES reporting formula collapses the categories of autism and other health impairment, finding that 55.8% of the students with those labels enroll in some form of postsecondary education. Consequently, data on the number of students who identify as having autism who enroll in higher education are unavailable. The general trends in the data suggest, however, that college participation for students with autism is rising.

Other studies have focused on the benefits, challenges, and experiences of individuals with disabilities who attend college or university programs (Casale-Giannola & Wilson Kamens, 2006; Causton-Theoharis, Ashby, & DeClouette, 2009; Hamill, 2003; Mosoff, Greenholtz, Hurtado, & Jo, 2007; Neubert, Moon, & Grigal, 2004; Schmidt, 2005; Weir, 2004). Recent research highlights the experiences and needs of students with autism on college campuses (Andreon & Durocher, 2007; VanBergeijk, Klin, & Volkmar, 2008), stressing the importance of determining a fit with the university, ensuring adequate social and counseling supports are in place, and providing intentional transition planning. College students with autism report challenges with housing and navigating the social milieu of the college campus (Andreon & Durocher, 2007). Further, new attention is being focused nationwide on college students with autism on college campuses through organizations including Achieving in Higher Education with Autism/Developmental Disabilities (AHEADD, 2010), which works to address those needs. However, even in these organizations, the focus is generally on students who identify with what is often referred to as
“high-functioning autism” or Asperger syndrome and who speak. The current study extends the professional discourse to include the population of students who identify as having autism and type to communicate.

Typing to Communicate

Typing to communicate, or facilitated communication, is a form of alternative and augmentative communication that has proven useful for some individuals with disabilities that do not demonstrate reliable verbal speech (Biklen, 1990, 1993; Biklen & Cardinal, 1997; Crossley, 1994, 1997; Mirenda, 2008). Typically, the individual with a disability types on a communication device or keyboard, while a facilitator provides physical, emotional, and communication support (Institute on Communication and Inclusion, 2000, 2010). For example, the facilitator provides physical support to slow or inhibit impulsive typing or to stabilize the arm. The person providing the support provides backward pressure, never leading the person toward the keyboard (Biklen, 1993; Crossley, 1994). The goal of facilitated communication is ultimately to develop independent, or near independent, typing and/or to develop the ability to read aloud the typed text (Institute on Communication and Inclusion, 2000, 2010).

Although many individuals who once required intensive physical support have developed the ability to type without physical support (Biklen & Burke, 2006; Kasa-Hendrickson, Broderick, Biklen, & Gambell, 2002; Wurzburg, 2004) or to read aloud their typed text (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick, & Hanson, 2009), the practice of supported typing has been controversial with some studies showing the potential for facilitator influence (Bebko, Perry, & Bryson, 1996; Bomba, O’Donnell, Markowitz, & Holmes, 1996; Cabay, 1994; Crews et al., 1995; Eberlin, McConnachie, Ibel, & Volpe 1993; Klewe, 1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Regal, Rooney, & Wandas, 1994; Shane & Kearnes, 1994; Smith & Belcher, 1993; Szemprruch & Jacobson, 1993; Wheeler, Jacobson, Paglieri, & Schwartz, 1993); others demonstrate that facilitated communication users can type novel messages without influence (Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuozzi, 1996; Weiss, Wagner, & Bauman, 1996). The challenges to authorship and validity of typed communication also can be viewed as challenges to the intellectual competence of individuals who type to communicate.

Rather than ability or disability being something that resides within a person, the authors presume that notions of competence emerge through the interaction of individuals with the larger sociocultural environment (Bogdan & Taylor, 1994; Collins, 2003; Goode, 1994; Hayman, 1998; Kliewer, 1998); in this case, the environment of inclusive higher education, which is uniquely positioned as a place where competence is tested and used as a prerequisite for membership. We do not contend that people considered to have significant disabilities are either competent or incompetent and that that competence could be tested and evaluated. Rather, we argue that competence, ability, and disability are socially constructed and highly dependent on the opportunities presented and the supports provided. Further, college classrooms, like K-12 settings, are sites of cultural reproduction, where ableist notions of normative performance reign. Ableism, or the persistent discrimination toward people with disabilities, based on normative assumptions of performance and ways of being (Ashby, 2010; Hehir, 2002; Rauscher & McClintock, 1997), can serve to limit access to higher education and access to needed supports. For example, college students are expected to speak in class, to complete lengthy written assignments similar to their
typical peers, and to initiate discussions with peers on course topics. Students with autism who type to communicate pose a challenge to those normative assumptions.

There are few published accounts of the experience of individuals considered to have significant disabilities in higher education (Biklen & Burke, 2006; Wurzberg, 2004), and there are currently no peer-reviewed studies of college students who use facilitated communication to engage in college. Our aim in this work is to begin to fill that gap in the literature by asking the following research questions: What are the experiences and perspectives of individuals who type to communicate in college and university settings? What are the strategies for success and barriers to participation within those settings?

METHODS

In order to explore the above research questions, we developed a qualitative study specifically employing in-depth interviewing (Bogdan & Biklen, 2006; Denzin & Lincoln, 2005) of the post-secondary students who type to communicate, along with their facilitators and support persons. Using purposeful sampling (Bogdan & Biklen, 2006), we conducted interviews with students at several colleges and universities across the United States, all of whom type to communicate as their primary means of expression and to complete academic coursework. We also conducted participant observations in college classes for some student participants in order to gain an understanding of their engagement in coursework. Other data sources include documentation from student participants related to their experience of higher education, for example, class presentations, assignments, and related writings.

Participants

We interviewed 14 individuals from five colleges and universities in two states. We selected our initial interviewees by contacting communication trainers around the country and asking for recommendations. Once we identified initial participants, they often directed us to additional college students who fit our criteria. The students included in this study have all been identified as autistic and received special education services throughout their K-12 or PreK-12 schooling. They are either currently enrolled or were recently enrolled in college or university programs. Some of the participants are non-matriculated students taking individual courses with support, others are enrolled in inclusive higher education programs where they audit courses on college campuses, and others are matriculated in degree-granting programs. All but one of the students are, or were, undergraduates, while one has already completed a bachelor’s degree and is working toward a master’s degree. The students enrolled in degree-granting programs had to apply and be accepted according to the same standards as their peers. It is important to note that the degree of communicative fluency and complexity varies among the students. See Table 1 for a description of participants.

We interviewed ten additional stakeholders, project directors, and facilitators, who support the students. These data provided needed background and information about the programs and services for the students enrolled in college. We have rich data from professors, program coordinators, and communication support people that have been reported in other articles (see, e.g.,
COLLEGE STUDENTS WHO TYPE TO COMMUNICATE

Table 1
Study Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>College or University</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craig</td>
<td>Starwood University</td>
<td>Current Student</td>
</tr>
<tr>
<td>Daniel</td>
<td>Sunnyside C.C.</td>
<td>Past Student</td>
</tr>
<tr>
<td>Diana</td>
<td>Starwood University</td>
<td>Current Student</td>
</tr>
<tr>
<td>Hannah</td>
<td>Collister University</td>
<td>Current Student</td>
</tr>
<tr>
<td>Josh</td>
<td>Sunnyside C.C.</td>
<td>Past Student</td>
</tr>
<tr>
<td>Leo</td>
<td>Starwood University</td>
<td>Current Student</td>
</tr>
<tr>
<td>Lisa</td>
<td>Willard College</td>
<td>Current Student</td>
</tr>
<tr>
<td>Marie</td>
<td>Sunnyside C.C.</td>
<td>Current Student</td>
</tr>
<tr>
<td>Nate</td>
<td>Starwood University</td>
<td>Current Student</td>
</tr>
<tr>
<td>Nia</td>
<td>Sunnyside C.C.</td>
<td>Past Student</td>
</tr>
<tr>
<td>Rachel</td>
<td>Landon College</td>
<td>Past Student</td>
</tr>
<tr>
<td>Raymond</td>
<td>Sunnyside C.C.</td>
<td>Past Student</td>
</tr>
<tr>
<td>Steve</td>
<td>Starwood University</td>
<td>Past Student</td>
</tr>
<tr>
<td>Tobias</td>
<td>Starwood University</td>
<td>Current Student</td>
</tr>
</tbody>
</table>

Causton-Theorharis, Ashby, & DeClouette, 2009). In this current study, we focus on the voices of the individuals with disabilities themselves as they narrate their own experience of higher education. Our decision to include in this article only data from college students who type stems from our commitment to honoring the voices of people often rendered silent in higher education.

Data Collection and Analysis Procedures

All interviews were digitally recorded and then transcribed verbatim. Follow-up interviews were conducted with participants to clarify information shared in a previous session or to expand on a topic. Interviewing individuals who type to communicate requires a different style of interviewing from conducting traditional spoken interviews. For example, questions were sent ahead of time so the participant could prepare thoughts before the interview, but all participants typed responses during the interview. We also asked fewer questions during each session and provided extended wait time, as facilitated communication is a laborious task, taking a longer time than verbal communication.

We conducted on-going coding throughout the data collection process to look for initial themes to explore and to develop follow-up questions. At the conclusion of data collection, all transcripts were inductively coded again. Both researchers independently coded the data and then the codes were shared. Those key codes were then refined and collapsed to arrive at the main themes presented in the following findings section.

FINDINGS

The study examines the four major themes derived from the data: (a) strategies for access and engagement; (b) the social implications of inclusion in higher education; (c) voice, validity,
and controversy; and (d) the promise of higher education. Themes are explored below with the narration of our study participants illustrating each theme.

“I need people to make me work”: Strategies for Access and Engagement

When it was time to begin Josh’s interview, both authors waited in the interview room and watched a challenging scene unfold in the doorway. Josh stood just shy of the door frame, his feet firmly rooted to the floor, repeating “no” over and over, seemingly unwilling to enter the conference room. His facilitator began by gently coaxing him, reminding him of the plan, encouraging him to take the first step into the room, all to no effect. Josh turned to his facilitator and typed the following statement, which his facilitator read aloud. “Force me to come in. Demand it.” His support person complied with this request, telling him firmly but calmly to enter the room. Josh braced himself and stepped forward. Each step into the room grew calmer, relaxed, and more even. When he sat down, we asked him to explain the exchange, to describe for us what he needs his support person to do. Josh typed, “Loud and clear. But don’t yell.” When we asked later about necessary supports for successful participation in college classes, he responded, “You saw it. I need people to make me work.” Josh desperately wants to be part of college, and he was clear about his need for particular, firm supports.

The juxtaposition of his bodily actions, verbal speech, and typed words is an example of the seeming contradictions for individuals who type to communicate. It also highlights a key support challenge. If someone took Josh at his words and actions, rather than his typed text, how many opportunities would be lost? It also demonstrates the complexity of academic support necessary in college settings for students like Josh. In this section, we outline some of the essential strategies for access and engagement as identified by the students with disabilities themselves. What do they see as important in ensuring meaningful engagement with academic content? This section highlights the importance of (a) visual supports, (b) grouping, (c) sensory and movement supports, and (d) communication with the faculty.

**Visual Supports**

One of the most frequently cited elements was the provision of visual supports in the classroom. Students described the importance of visual content to support the auditory. They need to see the notes presented visually, particularly with main ideas highlighted. Others expressed the need for pictures or visual symbols to support their understanding. According to Rachel, “I am wanting to see the words. I cannot help the babbling crowd.” When we asked for clarification, she confirmed that it was difficult to identify the important words to focus on in noisy classrooms and visual supports helped her attend to the key points. Still others advocated for greater integration of media, particularly videos, to support instruction. These findings highlight the importance of implementing principles of universal design in higher education, where information is provided in more than one modality and multiple means of response are allowed and encouraged. If it is difficult at times to parse out the important auditory information from the larger din of the classroom, visual cues can be especially helpful.
Another consistent theme from the students was the importance of opportunities for small group discussion. For many, sharing thoughts and ideas in a large group setting is difficult, but smaller, more intimate, groupings are more conducive to conversation and active engagement. This opportunity to process the course content in a discussion format also supported social connections and community.

Researcher: What could these professors do to make it successful?
Nate: Belong.

Researcher: Could you give me one specific example of belonging?
Nate: Include. In class discussion. Belong. Small groups.

Small group discussions open the door for connection among students and provide a sense of belonging. If connections with peers and supportive social networks are vitally important, organizing students into small groups, either in separate discussion sections or within the class, is a powerful class tool.

However, the importance of small group opportunities brings to light a challenge of these inclusive higher education programs as currently conceptualized. Although course selection is guided by student interest, many of the discussion-based, smaller classes are upper division courses and, therefore, have prerequisites for enrollment. That means that the non-matriculated students tend to participate in lower division courses, which are often much larger in size and feature a lecture format (Causton-Thoeharis et al., 2009). While this is a largely bureaucratic challenge, the material consequences are real. Students in the study describe the benefits of small class size, collaborative discussion, and meaningful connections with peers and faculty. However, those characteristics are often largely absent in large, lecture courses. This may leave the student isolated in the sea of other students with only the teaching assistant or facilitator as the collaborative partner. The students also report needing particular types of support from those facilitators.

Nearly every student interviewed commented on the importance of having a support person who understood her body and movement needs and who could help her stay in the class. For example, Diana stated, “I need someone to be able to read my body language and be supportive of being able to facilitate.” Diana makes subtle indications that she is ready to respond. She relies on her facilitator to watch for those signs—the slightly lifted hand, the eyebrow raise, eyes looking at the keyboard—and support those initiations with physical support to type. When Leo gets bored and has trouble keeping his body still in class, he “needs some sensory sometimes.” For some participants, this means frequent movement breaks during class. Others require deep pressure or joint compressions during class. Some students need to hold onto something during class to be able to focus. There is a growing body of research on the presence of sensory-motor challenges for individuals with autism (Dziuk et al., 2007; Green et al., 2009; Jasmin et al., 2009). This dyspraxia, or difficulty with movement or motor planning, can impact initiation,
bodily movement, transitions, as well as communication. The students need the support of trained facilitators who understand these sensory-motor challenges and can integrate sensory supports seamlessly into the college classrooms.

Nia has a plan for each class, a set of consistent procedures and routines that help her to stay focused. When she starts to lose focus in class, she said she needs her support person to “monitor me and remind me of the plan.” Lisa’s support person counts to three before they enter each classroom. She knows that on three it is time to enter and be part of the class. Lisa’s support people also provide verbal prompts to encourage participation. When engaged and responding to the lecture, her “autistic behaviors” diminish. Another essential support is the provision of additional wait time. Tobias explains, “She [his facilitator] has a real knack at easing my anxious body and mind when it takes me longer to do easy work, she just takes the time I need.” Other students report doing better when they receive the questions ahead of time so they can be prepared to share a response in class.

**Communication with Faculty**

These transition and academic supports are essential but are not typically provided in college classrooms. For this reason, several of the participants mentioned the importance of meeting with the faculty ahead of time to discuss the course expectations and needed accommodations. Diana shared,

> We chat about who I am, a little about my past, and I share that the Office of Disability Services will be sending along a letter containing my accommodations. Then it is my turn to ask about his/her expectations of their student’s content of their syllabus and so forth. I see this as a plus in engaging the words of who I am with the words of the expectations of a professor and the course.

Craig added, “My professors have a better understanding of my experiences when we can share communication with meeting person to person.”

University faculty need information on the depth and breadth of supports that help students who type to communicate to be successful in class. This may require a more active role than many faculty members are accustomed to. The second major finding is about the social inclusion of students in college settings.

“I am human”: The Social Implications of Inclusion in Higher Education

Several of the students’ previous K-12 educational experiences were marked by segregation and exclusion. This section describes the social contrast between K-12 education and college, the social isolation that still exists for many students at college, and the ways that students have found a social experience.
Comparing the Social Experience of K-12 to College

Many described the joy of being included in classrooms, alongside typical peers, doing “regular work” for the first time in their lives. During a presentation to a college class, Tobias described his experience of self-contained public school classrooms. “Self-contained classes are hell because they damage the soul. Hard to grow friends if you aren’t there.” He went on to discuss his high school career where he learned to “play Uno,” which he found to be ironic as “learning to play games by yourself is a lonely vocation.” Other participants echoed Tobias’ sentiments about the difficulty of social interaction due to public school exclusion. Nia shared a unique perspective when we asked her to compare her K-12 social experience with her college experiences. “It was hard then, too. But you are in one place so people know you better.”

According to Nia, it is more difficult to connect to peers on the college campus because in college you are with so many new people in many new environments. Particularly for non-matriculated students, there is not a sustained connection or interaction with a consistent group of peers. Other participants shared Nia’s perspective about the difficulty in creating and maintaining social relationships at the level of higher education.

Social Isolation in College

Involvement in higher education has not dramatically altered many participants’ social connections. Marie had been taking classes at a local community college. However, she was struggling to regain her confidence and comfort to re-enter the college classroom. She described the difficulties with the social aspect of college.

Researcher: What have been some challenges you have faced?
Marie: That I didn’t have friends.
Researcher: Can you tell me more about that?
Marie: That I wasn’t the only one alone.
Researcher: What made it hard to be friends with students there?
Marie: That I didn’t get to have fun.
Researcher: What would make it better?
Marie: Disabled students could really start a friends club.

Her interview highlighted one of the challenges of inclusive higher education programs. While Marie was included in classes and completing coursework with the support of her facilitator, she did not feel part of the campus social network. Marie was not alone in her feelings of social disconnection.

Researcher: Did you have the experience of talking to your peers about your disability or communication?
Raymond: No, They laugh at me.
Researcher: How did that make you feel?
Raymond: Sad and mad.
Researcher: What about your disability do people need to know?
Raymond: I am maybe normal.
Researcher: What do you mean by that?
Raymond: They have the problem.
Researcher: What would you want students to know about you?
Raymond: Always look at me.
Researcher: Why do you want them to look at you?
Raymond: I am human.

In these simple statements, Raymond asks us to examine the constructions of normalcy and to recognize the desire for a sense of belonging. He is simply asking for peers to look at him because he is human, desiring positive social interaction and connection.

Most of the participants shared that desire for social connections with their college peers, but one of the participants took the discussion of social connections in an unexpected direction. Lisa, a matriculated student in her 30s, typed the following:

Researcher: What do your facilitators do to help you connect to peers?
Lisa: Assume awful kids are not my peers.
Facilitator: How do you connect with them?
Lisa: Hoping not to.
Researcher: What would make peer interaction easier?
Lisa: For smarter kids.

Our questions highlight our assumption that she was seeking social interactions and connections with her university peers. Lisa’s last comment about “smarter kids” complicates those assumptions. Lisa is older than most undergraduates, and she was not desirous of friendships with these younger students; she went on to say that she found them immature and below her intellectually.

Social Opportunities in College

Lisa wrote an essay for a presentation that she was doing on this subject from her perspective as a college senior nearing the end of her studies in history.

An aspect of my life that has fueled my progress is attending college. When I first began taking classes I didn’t know what to expect, how would fellow students view me, would my distractive behavior consume me? Over the past five years of college my advancement has been remarkable. I have strived to become part of the college culture. Whereas students around campus used to gawk, I notice more now a sense of mutual respect. I have taken many classes at college and met many students. I am a history major and have recently been inducted into a historian’s honor society. Becoming more involved in school happenings has long since been a dream of mine. I felt a broader sense of belonging to the student community over the past year. I greet fellow students in the history
department by name, typing of course, and they reciprocate the gesture. My wish this spring semester is to participate more actively in history department meetings, social events and just simply to have lunch on campus.

It is interesting to note that Lisa’s perspective on peer connection has been fluid throughout her time in college. In this essay, she describes a mutual respect with her classmates and how she is becoming more involved on the campus. So, connecting back to Nia’s concerns, after time surrounded by peers, Lisa is beginning to enjoy a deeper sense of belonging and respect, even if these peers are not always her “friends.” Of course, these issues of connection and belonging are not unique to students with disabilities. Rather, undoubtedly most college students struggle with social isolation or discomfort at times.

When Craig was asked what others could do to help with the social issues that some have found difficult, he stated, “Initiate the suggestion of friendship.” This implies that others need to presume social interaction is on the minds of students and to make it a priority by helping to make social suggestions and presenting social opportunities. Lastly, Craig shared how facilitators need not only to provide social supports but also to learn how and when to fade that support to allow for natural interactions between students to occur. That delicate negotiation goes beyond the types of support typically provided for students with disabilities on college campuses. This emphasis on supporting social engagement necessitates provision of support outside of the classroom, in the social spaces college students inhabit.

“Let me choose my voice”: Voice, Validity, and Controversy

It would be an oversight to write an article on the inclusion of students who type to communicate in higher education without acknowledging the validity challenge many such individuals face. This finding is organized around (a) the controversy over typing to communicate and (b) gate-keeping in higher education.

The Controversy Over Typing to Communicate

For many facilitated communication users, initial access to higher education classrooms does not guarantee continued acceptance on campus. Nearly all of the students faced challenges to their competence and/or their method of communication, and some were not allowed to continue taking classes with typing support. Further, inclusion in higher education programs does not guarantee support for the method of communication. In this section, we discuss how students who type to communicate make sense of and negotiate these challenges to the acceptance of the method and, at times, the constructions of their own competence. While these communication aid users could be considered the lucky ones in that they have been able to access higher education and have typically had support for their method of communication, all of the student participants have faced challenges to the validity of their typed communication. Although that is not unique to the experience of higher education, it does cast a different light on what it means to be a college student.
Researcher: What is the worst part about using FC [facilitated communication]?
Josh: The controversy.

Researcher: What do we need to do to get the message out there? What do people need to know about FC?
Josh: Let me choose my voice. Back off.

Researcher: Who are you directing that to? Who do you need to back off?
Josh: Nonbelievers. Not your life.

For Josh, and nearly every participant in this study, access to communication support has been fraught with an emotional challenge. Many participants have been placed in segregated programs for students considered to have significant disabilities. Many have been presumed to have an intellectual disability. All of them have faced “nonbelievers” who challenged their communication and competence.

Many critics of typing to communicate argue that it is the person supporting the communication aid user, and not the user him- or herself, who is authoring the message. There are several issues at play here. One is the concern of physical influence by the facilitator simply due to the presence of touch. It is important to recognize that the possibility of influence does exist and steps need to be taken to mitigate those risks. Individuals who type to communicate and their facilitators should utilize Best Practice standards, including working with multiple facilitators, ensuring that the student looks at the keyboard when typing, working toward fading physical support, encouraging the typer to develop an independent yes/no or multiple choice point, and teaching the typer ways to protest when they feel their communication is being influenced. A full description of the Best Practices in facilitated communication is available through the website of the Institute on Communication and Inclusion (2011). The training standards are one resource for addressing concerns of influence and validity.

There is another undercurrent that cannot be ignored. Perhaps part of the reason these validity challenges are so potent is that there is an assumption that someone considered to have autism, or another developmental disability, and who does not speak, could not possibly be capable of producing such sophisticated text. This presumption of incompetence and concern about authorship is particularly interesting within the context of a college campus, when you consider that any time a student with or without a disability leaves the classroom to write a paper or complete coursework, there is the possibility of influence. There is the potential for completing the work in collaboration with a peer or even cheating directly. In other words, authorship could always be in question. However, the challenge to validity and authorship is something every one of the participants has faced.

Gate-Keeping in Higher Education

When we asked Josh to tell us more about these challenges to the validity of his typed communication, he described his interactions with the disability services office. After participating in several college classes and completing the work with the support of his facilitator with no challenge from faculty, his difficulties began when the disability services office became aware of the support provided by his facilitator.
Researcher: Has there been a difficult experience for you when you were on the college campus using FC?
Josh: Director of disabled services.
Researcher: Can you tell us more about that?
Josh: I have to prove it.
Researcher: What did you have to prove?
Josh: Smarts
Researcher: Do you want to explain?
Josh: Validate.

His facilitator went on to explain that Josh had been forced to undergo a “double-blind” test to validate the authenticity of his communication. In a double-blind situation, the facilitator and the facilitated communication user are shown different images and then the communication aid user is asked to type what he or she sees. The intention is to determine whether or not the facilitator is intentionally or unintentionally influencing the typing by encouraging the person to go toward letters in the word that the facilitator sees. Many of the participants described similar experiences of having to prove or validate their typed communication through some form of testing in order to stay in a class or remain on the campus. One of the students, Marie, had to type text independently (without physical support) to “prove” that she knew the content. Not unexpectedly, she was unsuccessful with this task. Marie requires the physical support of a facilitator; the pull back of her hand by the facilitator acts as a prompt to get started and a re-set to move on to the next letter. These types of high stakes testing situations are highly problematic for many individuals who type to communicate. The pressure of the testing situation can actually increase anxiety and make performance even more difficult. For a full description of the challenges of these types of tests, see Marcus and Shevin (1997).

When their method of communication was challenged, competence was called into question for these interviewees. Two of the students in this study stopped taking college classes as a direct result of these validation tests. One was not allowed to resume until she could type independently and validate her communication. The other was so shaken by the experience that he described being “unable to continue.” Rather than being incompetent, these students were rendered incompetent by the circumstances of these challenges. Prior to the validity challenges and communication testing, these students had been included in college level coursework and completed assignments alongside their typical peers with the support of a facilitator. They were just students in the class. However, once their method of communication was challenged, they were seen as potentially incompetent and forced to prove their right to be part of the college classroom. When they were unable to comply with the testing demands as constructed and denied provision of their communication supports, this reified the assumptions of incompetence that led to the testing in the first place.

It is interesting to note that the resistance to typing to communicate and the authorship challenges did not generally come from university faculty. Rather, several of the participants faced their greatest resistance at the hands of the disability services staff. The very office that is supposed to support the participation and accommodation of students with disabilities was often the gatekeeper.
Nia: My professors were fine with it but the department of disability services.

Researcher: What did you want to tell the folks at that office?

Nia: Don’t think they would like my words . . . They did not understand me. Someday I will prove them wrong.

Researcher: What do you wish they knew?

Nia: That I am a smart woman in a difficult body.

Nia refers to the sensory and movement challenges she experiences. Although she typed with minimal physical support provided at the elbow, during our interview she demonstrated difficulty initiating typing and required a verbal or physical prompt to both begin typing and to finish her thought. As discussed earlier in the article, many individuals with autism report difficulties with intentional movement (Biklen & Burke, 2006; Blackman, 1999; Mukhopadhyay, 2000; Williams, 2003). Unfortunately, these movement challenges (Green et al., 2009) have frequently been misinterpreted as incompetence (Donnellan & Leary, 1995), and the validity of communication has been challenged. As Nia describes:

My first class was an art history class that I took in the Fall of 2000, and then I took a second art history class in Spring 2001. I got an A in both classes and being that I got good grades and that I like school I was motivated and enrolled in more classes like psychology, but it didn’t go well because the school started to test me with the double blind test. Things started changing for me as a consequence, my whole attitude changed.

We include one last example of a less direct, but no less painful, affront to typed communication by one of Lisa’s professors. While he was not the only one to question her typing, this professor actually included the practice of facilitated communication as an example of a “bizarre belief.” When I asked her to explain how she knew her faculty did not believe in her typing she responded, “It was not hard to tell. One teacher included it in the curriculum. FC as bizarre.” We were incredulous at this professor’s willingness to discredit Lisa’s communication publicly, within the context of academic curriculum. Fortunately for Lisa and most of the others in this study, those challenges were not the norm. For most, inclusion in college was marked by new opportunities and heightened expectations.

“The equality I was waiting for”: The Promise of Higher Education

In this section, we examine the subthemes of (a) the differences between K-12 and higher education, and (b) constructing competence in higher education.

Looking Back to K-12

Hannah shared that she was glad to be “in a school where they had the belief in these students who could need much assistance . . . I am given the same opportunities and held to the same expectations as any other student.” While it may not seem surprising that college students would feel more challenged by the academic demands, the difference was striking. When Leo was asked
to describe his college classes, he said, “Really hard sometimes, but so much better than high school.” Leo went on to describe his high school in more stark terms.

Yes, a school should be what we all love. But my experiences about broke my freaking real soul. I was treated like shit. I mean like a dumb ass and I loved to learn so I freaking dead inside . . . Please know that self-deading places are hard places to make progress and learn stuff because they don’t have people wanting your child to really learn anything except person place or things . . . nouns I know. That’s my take. But I’m just one person. I know lots of people love those rooms. More often they just play games like Uno.

For these students, inclusion in higher education was a marked departure from the monotony of segregation and low expectations.

While not surprising, this research clearly indicates the importance of a presumption of competence (Biklen & Burke, 2006; Jorgensen, 2005; Snow, 2009) for individuals who type to communicate. A presumption of competence approach holds that even in the absence of concrete evidence, we have to assume that people labeled with more complex disabilities are capable of far more than they are currently able to demonstrate, given the available supports. Then it is incumbent on teachers, parents, and support people to create access to meaningful experiences and opportunities for that competence to be made visible. Access to higher education classrooms is contingent on scheduling and facilitator support and also on the attitudes of the college professor toward the method and toward individuals who do not demonstrate reliable verbal speech. Many participants, particularly those taking courses, but not matriculated in degree-granting programs, had experienced highly segregated schooling. In this way, their understandings of their competence were greatly altered in this new context. Raymond describes his K-12 experience:

Researcher: In K-12, what did you want them to know about you that they didn’t know?
Raymond: I am smart.

Researcher: Do you think they didn’t know that? What made you think that?
Raymond: Looks of pity.

There are no “special sections” of History 101 at these universities. Simply being in academic classes alongside typical college peers was a shift from previous educational experiences. We were struck by the simplicity of what these students were asking for from their professors at times. Some wanted their professors simply to interact directly with them. Others expressed the desire to be seen as competent students with potential to contribute.

Constructing Competence in Higher Education

We asked every interviewee what they would want their current or future professors to know about them and what helps them or would help them be successful in the arena of higher education. Some of their responses were focused on specific strategies of grouping arrangements. Some focused on the role of supporting social connections. Some, like Ben, just wanted their faculty to know they were capable and worthy of higher expectations.
Researcher: If you came to my campus and took classes from me. What would I need to know about you in order to make that work for you?

Ben: I am smart. Try me.

Ben is simply asking to be seen as a student with potential, similar to his college student peers sitting next to him in class. He did not describe a complex set of expectations or individualized needs, rather an assumption of competence and access to academic opportunity. Lisa stressed the importance of a rigorous academic program in keeping autism at bay. She argues that engaging her mind helps reduce the manifestations of autism that can take over at times:

The value of an academic program should not be underestimated. I believe my mind was able to rewire itself because of academics. I needed to be able to focus before learning could occur, but I positively didn’t need a repetitive program to achieve this. By being in regular classes and wanting to be successful, I was able to force autism to let me be.

How often do we read about children or young adults denied access to typical classrooms until they can demonstrate the ability to “control their behavior” or “interact appropriately with peers?” Lisa casts a very different light on this issue, arguing that it was inclusion in classrooms with meaningful academic content and expectations that helped her behavior to change. These interviews for this research study were not short; we spent up to two hours typing and talking with these college students. Yet, every one of them was able to stay in the room, listen to the questions and respond thoughtfully. They knew we were taking them seriously and viewing them as the experts on the experience of college for individuals who type to communicate.

IMPLICATIONS

Please know for me and for others, it is profoundly vital to not give up on the ideal to move us quietly through the door of opportunity, when there may be those who have their toe pressed against it. For if you allow us to go through it, it must be a full and complete entrance. (Craig, Starwood University student)

The implications of this study are relatively straightforward. The more we understand the experiences of individuals who type to communicate, the better equipped we will be to “remove our toe from the door of higher education” to allow these students full access to the rich academic and social experiences innate in the college setting. Implications exist for students who type to communicate, their parents, facilitators, their peers, college and university administrators, professors, and future employers.

The first step for all potential stakeholders is to understand that this new generation of college student exists. In the past, these students were either rejected from higher education, or they did not apply in the first place. Therefore, students and their parents can begin to dream of higher education from early on. K-12 professionals need to prepare all students for this potential by making the K-12 experience preparatory of higher education and not segregating these individuals from the general education setting. This means moving thousands of students out of a segregated “life skills type” education and providing them a rigorous college preparatory experience if so desired. It also means making thoughtful modifications and adaptations to allow genuine access to content and social experiences.
Colleges and universities need to be prepared to welcome students, remove barriers, and provide support for the on-going college experiences for all students, including this population. This research indicates the importance of a presumption of competence for individuals who type to communicate. Therefore, the second major implication is the importance of getting all stakeholders to understand that these students are competent individuals with a right to be at institutions of higher education. We have seen that access to college classrooms is not only contingent on scheduling and facilitator support; it is also dependent on the attitudes of the college professors and disability services staff toward the method of communication and toward individuals who do not demonstrate reliable verbal speech.

When considering the social access to higher education, numerous realities come into play, including the time it takes to communicate, the impact of facilitator support on peer interaction, and the need to be acclimated to the larger college. These data suggest the importance of helping peers “see these students as humans” and not as visitors to the classroom who can be ignored. Lisa suggests that it might be useful to help others understand potentially distracting behavior. Further, college professors and facilitators could help “smooth the way for friendships and stand back.” (Craig)

Some of the data suggest that the types of classes are important. The course selection, size of class, and format of engagement (i.e., discussion, lecture, observation) make a difference for these students. Students also discussed the type of supports as important to their meaningful engagement. For example, what facilitators did to support the participants’ body, movement, and emotional state were all considered important. Working with disability services offices and the modifications and adaptations to course work also were important considerations. Clearly, faculty and administrators in college need additional training about the kinds of supports that may be necessary for someone who types to communicate. The participants in this study are the pioneers in this field, but this also leaves them with the responsibility of having always to be the first. That is an immense pressure and burden on top of the struggles that typically accompany college participation. We might consider how other students can act as allies in the quest for access.

As colleges and universities encourage increased diversity in their students and faculty, this is yet another aspect of diversity that must be considered. Ableist assumptions of performance (Ashby, 2010; Hehir, 2002) that assume all college students need to speak need to be called into question. College is a place to broaden perspectives, consider new ideas, envision the world as it could be. This commitment to communication diversity is in line with this mission. Just as we need to have more classrooms where American Sign Language interpretation is provided, or large print versions of texts are used, this study suggests the importance of valuing and supporting typed communication. See Table 2 for a list of suggestions for making inclusion in higher education both possible and successful for students who type to communicate.

LIMITATIONS AND FUTURE RESEARCH

This study is an important step in bringing the voices of individuals who type to communicate to light within the backdrop of inclusive college campuses. However, one limitation of this study is that it relies primarily on interview data. While we conducted observations in the classrooms of a couple of participants to develop a sense of the broader university context, we did not observe all
TABLE 2
Effective Practices in Inclusive Higher Education for Students who Type to Communicate

| Campus Culture and Climate                                                                 | • Include disability in Campus Diversity Policies |
|                                                                                           | • Provide campus-wide education on supports for students with disabilities |
|                                                                                           | • Connect with disability rights and advocacy groups on campus or start one |
| Training and Support                                                                       | • Provide training on facilitated communication and academic supports for classroom support personnel who interact with students who type |
|                                                                                           | • Familiarize personnel who provide services for students with disabilities with the most recent research on supported typing and strategies for success for students who type to communicate |
| Course Selection                                                                           | • Consider smaller, discussion-based courses rather than large lectures |
|                                                                                           | • Develop ways for students to learn the course structure so that students make better informed decisions about fit |
| Getting Ready                                                                               | • Students could develop a short description of needed supports that can be shared with faculty and support staff |
|                                                                                           | • Students should meet ahead of time with university faculty to review the course structure and expectations and to provide information about classroom needs |
| Seating and Group Arrangement                                                               | • Provide opportunities for small group interaction |
|                                                                                           | • Ensure proximity to instructor, but provide flexibility and opportunity for movement if necessary |
| Classroom Supports                                                                         | • Provide visual supports (Powerpoint, agenda, graphics) |
|                                                                                           | • Integrate media |
|                                                                                           | • Incorporate principles of universal design |
|                                                                                           | • Share presentations ahead of time so the student can plan some responses to share in class |
| Social Opportunities                                                                       | • Provide adequate support to engage in non-curricular events on campus |
|                                                                                           | • Schedule transportation to allow for social time on campus |

of the student participants in college settings. Further, we have included very limited data from those classroom visits. This was an intentional decision as we were interested in the perspectives of the students. Future articles will focus on the actual classroom experiences of individuals who type to communicate and the structures and strategies that make meaningful engagement in higher education coursework possible.

A second limitation involves the data collection process. As the students were not all attending college in the researchers’ home state, we traveled to meet these participants and conducted the interviews in comfortable locations near their homes. However, as this involved interstate travel, any needed follow-up was conducted via e-mail. Although not ideal, this procedure allowed us to include many more students from other parts of the country. As there are relatively few students who type to communicate enrolled in college programs, we wanted to cast the widest net possible and include individuals from far afield, even if that complicated data collection. Additionally, it may be important to interview peers, disability services staff, and professors to gain a broader perspective on the inclusion of this population of students. As this is a relatively new population
of college students, it would be important to do follow-up studies with these students to see how higher education impacted their professional and social lives after college.

CONCLUSION

Higher education is a different frontier from K-12 schooling. There are not laws mandating college acceptance; there are no zero-reject policies at most universities. There are acceptance requirements that need to be adhered to and this raises additional questions about authorship, validity, and gatekeeping for individuals who type to communicate and require the support of a facilitator. We are still in the beginning stages of creating truly inclusive college classrooms. Traditional assumptions of what it means to be a college student persist; campus offices for the provision of services for students with disabilities are not yet accustomed to providing trained facilitators; professors are not used to structuring their classrooms to encourage meaningful participation for individuals who do not speak. But the time is now. There are more and more students pushing against the doors of higher education classrooms. We have to help remove those barriers to access so that all students, including those who type to communicate, can experience all that higher education has to offer.

NOTES

1. All names of individuals have been changed to ensure anonymity.
2. Many terms are used interchangeably for the act of typing to communicate. These include “supported typing,” “typing to communicate,” “typing with physical support,” and “facilitated communication.” Much has been written on facilitated communication in particular. While no language is perfect, in this article we will use the term “typing to communicate” or “types to communicate.” However, we use the term “facilitated communication users” to discuss those who use typing to communicate if that is how they define themselves.
3. All names of colleges and universities have been changed to ensure anonymity.

REFERENCES


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