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Disclosure and Self-Advocacy in Higher Education: Emerging into Adulthood with a Disability

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Abstract: A study of learners with disabilities in postsecondary education moving from dependent special education K12 students to self-authored adult learners reveals complex disclosure and self-advocacy interactions with faculty, peers, and disability staff.

Keywords: disability, postsecondary education, emerging adulthood, self-authorship, disclosure

Introduction

As more students with disabilities enroll in postsecondary education (Getzel, 2008; Lightfoot, Janemi, & Rudman, 2018), the demand for meeting their needs grows. These learners face unique obstacles to success and need the opportunity to study in supportive environments with trustworthy and informed faculty and peers where they are not defined by their disabilities.

The goal of this research is to explore how learners with disabilities coming from special education experiences, controlled by school and parents, navigate learning differently in higher education as they come to see themselves as adults with disabilities who can find their place in postsecondary academia. The following research questions guided the study: (1) How do college students with disabilities navigate postsecondary education in ways that represent their coming to adulthood? (2) How do disclosure and self-advocacy interactions shape the progress of college students with disabilities? (3) How do past disability related experiences in special education and current disability related experiences in higher education affect these learners?

Despite literature on the transition of students with disabilities from high school to college (Reed, Kennet, Lewis, & Lund-Lucas, 2011), disclosure of disabilities in higher education (Kerschbaum, Eisenman, & Jones, 2017), emerging adulthood (Arnett, 1994), and self-authorship (Baxter Magolda, 2014), there is a gap regarding how disclosure interactions of postsecondary students reflect their move from adolescence into adulthood.

Methods

The participants of this study are students attending a small state university in the Northeastern United States. Their disabilities include autism spectrum disorder, auditory processing disorder, dyslexia, dyscalculia, attention deficit hyperactivity disorder, neurological motor disorder, degenerative spinal stenosis, depression, and diabetes. They received disability support services during their K12 schooling and disclosed their disability to disability services at the university. Participants attended a focus group on the experiences of college students with disabilities or participated in a semi-structured personal interview. The discussions provided students a chance to discuss significant issues such as disability disclosure and advocacy in higher education, becoming an adult by practicing self-determination and responsible decision-making, and creating inclusive environments for marginalized learners. Both the focus group discussions and the personal interviews were recorded, transcribed, and analyzed thematically.

Initial Findings

Students developed a clear understanding of their disability needs despite a lack of decision-making power and rejections of their self-advocacy requests. While they appreciated parental, disability staff, and advisor support, they expressed a strong desire to decide on their own course choices, career paths, and living arrangements, even if those decisions might lead to

difficulties they would have to overcome. They recognized the value of learning from their own mistakes. In her interview, Lucy revealed that her advisor told her that her career goals were unrealistic. She said, “I do have extraordinary circumstances, [but] once upon a time, you know, nobody [had] ever walked on the moon either. I know I shouldn't let one person affect me, but to hear the field professor say that [was] not helpful.... I love to be the exception.... I mean, you can do anything and that sounds really cliché, but just don't let it stop you.” As a mature senior who has expressed acceptance of her body’s limitations, Lucy is applying for jobs in her chosen field and planning to move across the country, rejecting advice that would limit her options.

These learners with disabilities easily recognize the traits and skills of university faculty and staff that support their needs and compensate for the lack of these characteristics when they face unsupportive individuals. Participants were most successful when their professors were patient, empathetic, knowledgeable, and focused on positive student attributes rather than deficits. Despite being a very slow reader due to his dyslexia, Kip was encouraged to persevere by “teachers [who] told me I was able to comprehend the things I was reading better than some of the other students.” On the other hand, Alex described returning to class after back surgery when her professor “wouldn't let me make up work even though I had a doctor's note.... It got to a point where I was like, there's just no use in explaining cause they're not going to be understanding. I feel like they didn't believe me either because I was up and walking.... I didn't want it to get to the point where I was going to have to argue with them or explain further. So I just kind of left it, and I ended up failing.” It can be less stressful and physically draining for the participants to accept failure than experience repeated confrontations.

Viewing themselves as responsible adults, these postsecondary learners with disabilities are frustrated by university personnel and peers who do not believe the veracity of their disclosure statements. They became exasperated and angry when their disability needs were not recognized because they did not outwardly present as individuals with disabilities. Emily said, “I tell people I have a disability issue and they look at me and they don't see anything physically wrong. They think I'm just fine. I don't have to walk with a cane or a walker to be disabled ... there's a range of disabilities out there. It's kind of like people have ... this image in their head of what it's like. [You're] supposed to look the part.” The participants want members of the university community to become more informed and recognize the diversity of disability.

Conclusion

The preliminary results of this study provide insight into effective ways of supporting postsecondary learners with disabilities in developing an understanding of themselves as adults with disabilities and in achieving academic and social success despite their disabilities.

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