

“It’s Bigger Than Me:” Influence of Social Support on the Development of Self-Advocacy for College Students with Disabilities

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Abstract

As the number of college students with disabilities continues to grow, self-advocacy programs have become an increasingly important tool to help students access disability-specific and general student services. Yet, few studies have explored processes surrounding the development of self-advocacy for students with disabilities, in particular the role of social support in fostering important knowledge and skills. In this study, we conducted semi-structured interviews with 28 students receiving disability services (DS) from a large Hispanic serving institution (HSI). Our analysis yielded findings related to four subcomponents of self-advocacy, (a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. Students attributed formal and informal social support to their progression in each area, distinguishing between initial and advanced phases of self-advocacy development. Recommendations for future research and implications for secondary and postsecondary education are provided.

Keywords: self-advocacy, social support, college students with disabilities, qualitative interviews

Over the past few decades, postsecondary enrollment rates have increased for students with disabilities (Newman et al., 2010). The most recent national data show that 19.4% of undergraduate students and 11.9% of graduate students report having a disability (U.S. Department of Education, 2020). Still, graduation rates, especially at 4-year universities, continue to be low (Newman et al., 2009). Among other factors, research has found that both disability-specific services (e.g., accommodations) and general student services (e.g., tutoring) are associated with higher grades and graduation rates (Dupaul et al., 2017; Newman et al., 2019; Troiano et al., 2010). However, only about 22% of students who received disability-related services in high school received accommodations at 4-year colleges (Newman & Madaus, 2015), and only 53% of students with learning disabilities (LD), the largest subgroup of college students with disabilities, received general student services (Newman et al., 2019).

Given that the receipt of such services is dependent on students either disclosing their disability or

actively seeking assistance, researchers have identified self-advocacy as a critical component of postsecondary success (Gelbar et al., 2020; Getzel & Thoma, 2008; Ju et al., 2017). To foster self-advocacy, researchers have developed various programs, designed for students in secondary (Cuenca-Carlino et al., 2019; Doren et al., 2013; Holzberg et al., 2019; Rowe et al., 2021) and postsecondary settings (Hsiao et al., 2018; Parker & Boutelle, 2009; Walker & T

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four subcategories of self-advocacy—(a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. Often, self-advocacy

measures put in place in response to the COVID-19 pandemic. Our research team, a faculty member and two graduate students, communicated with participants via email, phone, and video conference (i.e., Zoom). We placed consent procedures and a demographics survey on QuestionPro, an online survey tool, and gave students the option of completing interviews on the phone or video conference. A little less than half (43%, $n=12$) chose the phone and over half (57%, $n=16$) chose video conference. For video interviews, the interviewers, the first and third authors, chose to display the plain walls of their workrooms as the background with their faces taking up most of the foreground. Participants joined from their offices, couches, or dining room tables.

Participants

Per the university's disability services (DS) center, approximately 1,300 students (i.e., 1,100 undergraduates and 200 graduates), or 5% of the overall student body, receive accommodations or support services for a documented disability. All students with a documented disability were eligible to participate in the study. Consulting previous literature (e.g., Pfeifer et al., 2020), we sought a purposive sample of between 15 and 30 participants with a goal of having representation from each college at the university, demographics representative of the student body,

Table 1*Participant Demographics*

Category	Percentage
Gender	
Female	75% (n=21)
Male	25% (n=7)
Race/Ethnicity	
Hispanic	71% (n=20)
White	25% (n=7)
Black	4% (n=1)
Age Range	
18-22	29% (n=8)
23-29	29% (n=8)
30-39	21% (n=6)
40 and over	21% (n=6)
College Level	
Undergraduate	57% (n=16)
Graduate	43% (n=12)
Degree Field	
Liberal Arts	29% (n=8)
Health Sciences	29% (n=8)
Science	18% (n=5)
Education	11% (n=3)
Business	7% (n=2)
Engineering	7% (n=2)
Disability	
Multiple Categories	36% (n=10)
Medical Condition	25% (n=7)
Emotional or Psychological Condition	18% (n=5)
Learning Disability	14% (n=4)
Other	7% (n=2)

ground, (b) development of self-advocacy, and (c) role of social support. T

Table 2

Semi-Structured Interview Questions

Topic	Guiding Question
Background	<p>Can you please describe your background, disability (if comfortable), and college experience?</p> <p>Can you please describe your experience seeking and receiving disability-related and/or general student services in college?</p>
Self-Advocacy	<p>If applicable, can you please describe your experience receiving disability-related services in grade school or the workplace?</p> <p>What does self-advocacy mean to you (provide an example)?</p> <p>How has your ability to self-advocate changed over time?</p>
Social Support	<p>What factors have helped or hurt your ability to learn and enact self-advocacy?</p> <p>What does social support mean to you (provide an example)?</p> <p>Who are your key social supports? How have they changed over time?</p> <p>Who supported you?</p>
Combined	

I had been dealing with voices in my head for about 11 years without treatment...it comes with some kind of stigma, and I didn't want to deal. But me not dealing with it has led to many problems like drug abuse, alcohol consumption.

Different forms of stigma impacted students' decisions to seek support such as accommodations in college or the workplace, counseling or therapy, or guidance from friends and family. When requesting accommodations with DS in college, students often reported feeling undeserving. For example, Juliet, a graduate student with emotional and psychological conditions and a seizure disorder, reflected on her thought process.

The stigma was too big at the time. And I thought, 'No, I don't need it [DS]. Some people need it, and it would just be taking advantage of the system.' I guess I had internalized a certain discourse that my family had been feeding me throughout my life.

After receiving services in college, many students felt validated. However, others continued to feel uneasy. Diana, a graduate student with depression and anxiety, said, "I still do resist using the accommodations. I guess I still associated some sort of stigma to using them."

As students negotiated stigma and initial self-advocacy experiences, they were able to research their disability and self-reflect, gaining additional knowledge of self. Some students researched on their own, and others did research as part of a college course. Having heard about his ADHD at meetings in grade school, Justin, now an undergraduate, took it upon himself to do independent research. He said, "It wasn't until middle school when I just kind of figured it out myself by Googling it." Others discussed doing research later in life, including in college courses that addressed the history and science surrounding disability. Research and reflection often contributed toward feelings of self-awareness and, in some cases, empowerment. For instance, Maria, an undergraduate identified with dyslexia, described how learning about neurodiversity helped her with acceptance. She explained her current viewpoint, saying, "It just takes me a little bit longer to read something than it would take someone that's neurotypical." Others described how self-awareness helped them gain confidence in their strengths over time. George, who was identified

with LD and anxiety in grade school, was a successful business owner, seeking his second master's degree in science. He reflected, "I'm a stickler for self-improvement and development. And I'm always fond of learning, even if it doesn't come easily at times." Students often attributed their empowerment to succeeding in situations that required self-reliance or perseverance, such as entering adolescence or adulthood, beginning undergraduate or graduate studies, or starting a new job.

Along with research and self-reflection, many students drew on social support in their process of gaining knowledge of self. Students drew from both formal (e.g., counselors, DS staff) and informal (e.g., friends, family) supports. Often, personal connections with informal supports helped students gain the confidence to seek formal support. For instance,

Knowledge of Rights

Knowledge of rights is defined as an individual's knowledge of their personal and educational rights, along with their knowledge of disability-related policies, services, and accommodations (Test et al., 2005). Along with knowledge of self, knowledge of rights is necessary for students to self-advocate for appropriate services in college. In this study, students tended to gain knowledge of rights through interactions with knowledgeable sources and experiences advocating for services. Some became experts in the nuances of laws and policies, while others gained just enough information to navigate their unique circumstances. The following sections discuss common themes related to the development of knowledge of rights.

Most students expressed having limited knowl-

While accommodations are provided, there are sneaky managers and sneaky companies out there that may loop around it and get rid of you if you're not able to compete with the rest of their staff.

went to the

Beyond disability-related policies, many students also discussed a knowledge and passion for addressing other topics, including immigration, health care, and veterans' rights.

Communication

Communication is defined as an individual's ability to express themselves, including their disability and rights, to others with an effective level of assertiveness (Test et al., 2005). Communication for self-advocacy relies on having a strong knowledge of self and rights. Although all students in the current study had the communication skills to receive an official evaluation for a disability and register for accommodations, they had differing experiences learning to communicate and differing preferences. Many gained initial and more advanced skills through encouragement from formal and informal supports, honing skills through experience self-advocating. The following sections describe common themes related to the development of communication.

Although a few students expressed having naturally strong communication skills, most attributed their development to encouragement from others. Often, students mentioned a specific individual who supported them through their first experience self-advocating. For some, this was a professional, such as a teacher, librarian, counselor, or professor. Adriana described how a high school teacher influenced her.

Having a teacher that advocated for me before I even started advocating for myself, proved to me that it's a normal conversation and that people notice. If she hadn't done that, I probably wouldn't have initiated conversations with a lot of people.

For others, a family member or close friend helped initiate communication. Conversations with informal supports often gave students the confidence to speak with others and seek services for the first time. For Liliana, her sister provided the emotional support necessary to communicate her needs with professionals.

When I first went to [the evaluation center], I didn't really want to admit that I needed, like, help talking things through. And so, she [sister]

Tammy described being tactful, letting others know about her accommodations early, to avoid crises with her diabetes.

I don't want there to be a problem in the future. And so, I try to be prepared not only by making sure I always have snacks and drinks with me. But also making sure that other people are aware in case something happens.

Even with strong communication, students experienced continued challenges, including burdensome paperwork, unsupportive individuals, and inaccessibility. Alice described the lengthy process of requesting appropriate services that strained her communication efforts.

It was kind of pulling teeth to get there initially. I had to request multiple times. Because I would request for say three different accommodations, and I'd only get one on the record... so it's been kind of a process of addition.

Similarly, Jose explained the burden of constant communication with university, medical, and government systems to receive services. He said, "I try [to communicate]. I think it'

Once in the career, students were able to apply life lessons to their work. Juliet explained that her experiences in special education as a child helped her become a more understanding teacher.

My personal experience has helped me empathize and listen better to other people. And I'm here to help my students. I'm not here to impose or threaten any type of power, I'm here to guide them, and they are all individuals. Everyone

of supports helped students develop the self-advocacy necessary to navigate challenging situations and systemic barriers (e.g., multiple forms of stigma, inaccessible contexts, burdensome policies; Grimes et al., 2020; Hong, 2015; Mamboleo et al., 2020).

Importantly, we identified multiple students who received support from empowerment agents (Stanton-Salazar, 2011), such as teachers or professors who went above and beyond their typical duties to advocate for students from marginalized backgrounds. Participants who were first-generation college-going students especially benefitted from this support in accessing DS, counseling, or other general student services. Often, these students stated that their informal support networks lacked the social capital to access these services. Furthermore, although not all students

ous reasons. Although many participants in our study shared their experience of not self-disclosing, often for years, the perspectives of students who never disclosed were not captured by this study. Additional research should address these perspectives, perhaps through longitudinal studies with students who received disability-related services in grade school. Third, our findings may be limited due to the use of phone and video conference interviews rather than in-person methods. Although we suspect that there may be value to conducting qualitative interviews remotely, especially with individuals with disabilities, that should be studied further (e.g., ease of scheduling, increased accessibility, comfort in participating from home), we acknowledge that some individuals may prefer in-person interviews and may have been more open in interviews if they had been able to meet the researchers in-person.

Conclusion

Interviews with 28 college students

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