

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

Kristopher Hawk Yeager<sup>1</sup>  
Gabriela Alejandra Gandara<sup>1</sup>  
Cecilia Martinez<sup>1</sup>

## 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 & Test, 2011). However, more common than direct instruction, students tend to develop self-advocacy through trial and error with ongoing support from friends, family members, and caring professionals (Daly-Cano et al., 2015; Ju et al., 2017; Kimball et al., 2016). Additional research is needed to better understand how support from others influences self-advocacy development for college students with disabilities.

## Literature Review

Our research is guided by a conceptual framework developed by Test et al. (2005), who identified

<sup>1</sup> University of Texas at El Paso

four subcategories of self-advocacy—(a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. Often, self-advocacy is considered a subset skill under the self-determination umbrella, which includes other important skills such as choice-making, problem-solving, and goal setting (Wehmeyer, 2005). However, we also draw on more recent work by Trainor (2017) who argued that self-determination is not just a set of skills but “a set of ways of knowing and doing” (p. 117), which are largely influenced by one’s social and cultural context. Multiple studies support the notion that students learn and enact self-determination and self-advocacy in different ways depending on their cultural, linguistic, and socioeconomic backgrounds (Banks, 2017; Murray & Naranjo, 2008; Yamamoto & Black, 2015).

Depending on their backgrounds, students also have varying access to social support (Stanton-Salazar, 2011), which researchers have identified as an important contributor to self-advocacy development (Lombardi et al., 2016; Scorgie et al., 2010; Stein, 2012). Sarason and Sarason (2009) argued that social support provides a buffer to stress and the sense of attachment necessary for individuals to take the risks needed for personal growth. For college students with disabilities, social support is not only associated with higher levels of self-advocacy but also increased levels of college adjustment and academic performance (Lombardi et al., 2016; Murray et al., 2013). Furthermore, qualitative studies have found that supports can act as role models for initiating self-advocacy and sources of encouragement for persistence in self-advocating behaviors (Daly-Cano et al., 2015; Getzel & Thoma, 2008; Kimball et al., 2016).

Inversely, through negative interactions, individuals or groups can act as barriers to support, hindering a student’s development of self-advocacy (Banks, 2017; Grimes et al., 2020; Hong, 2015; Lightner et al., 2012; Mamboleo et al., 2020). Experiences with stigmatization, low expectations, or discrimination from educators or peers in secondary or postsecondary settings can contribute to a desire to shed disability labels and avoid services (Banks, 2017; Grimes et al., 2020). Additionally, when students perceive college faculty and staff as intimidating or uncaring, the process of self-advocacy can become overly burdensome (Hong, 2015; Mamboleo et al., 2020). Thus, if college students decide to disclose their disability, they often wait until they experience a crisis or until they identify a supportive individual who can act as a facilitator (Lightner et al., 2012). Stanton-Salazar (2011) used the term “empowerment agents” to describe these types of individuals who support individuals from marginalized backgrounds and use their social capital to advocate for systemic change.

Although social support and the development of self-advocacy for college students with disabilities are clearly linked (Daly-Cano et al., 2015; Ju et al., 2017; Lombardi et al., 2016), there is a need for additional research clarifying the extent of this relationship. In particular, there is a need to explore the role of social support in the development of each of the four components of self-advocacy (i.e., knowledge of self, knowledge of rights, communication, leadership; Test et al., 2005). Recent work by Pfeifer et al. (2020) explored the four components of self-advocacy with college students with attention-deficit/hyperactivity disorder (ADHD). Knowledge of self and knowledge of rights tended to promote the development of skills in communication and leadership with agency acting as a moderator (Pfeifer et al., 2020). For college students with various disabilities, the current study expanded on these findings by detailing the way self-advocacy develops over time, considering student perspectives on the influence of social support. The research addressed the following questions:

**Research Question 1:** How do college students with disabilities develop self-advocacy?

**Research Question 2:** How does social support contribute to the development of self-advocacy?

## Methods

The focus of our study was to explore the influence of social support on the development of self-advocacy for college students with various backgrounds and disabilities. We employed a basic qualitative methodology to gain insight into key stakeholder experiences (Merriam, 2009). Semi-structured interviews (Creswell, 2014) and a collaborative coding process (Saldaña, 2016) helped isolate four specific components of self-advocacy and overarching themes related to their development (Test et al., 2005). Using this methodology, we were able to highlight the diverse voices and experiences of individuals with disabilities, a growing field of study in secondary (Gonzalez et al., 2017) and postsecondary education (Ju et al., 2017).

## Setting

The setting for the research was a large Hispanic Serving Institution (HSI) in the Southwest that enrolls approximately 25,000 students. Of the overall student population, approximately 80% are Hispanic and 50% identify as first-generation college-going students. The surrounding community has a high percentage of bilingual and binational residents. Research activities took place virtually due to safety

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, and participants with a wide range of disabilities. Our goal was to identify students with diverse knowledge, skills, and experiences related to self-advocacy. Through the DS email listserv, students received an initial email invitation to join the study. Then, they received two follow-up emails about two and four weeks after the initial invitation. In total, 33 students responded via email to the first author indicating interest or questions about participating, and 28 students chose to complete consent procedures and all study activities.

Each item on the demographics survey had a "prefer not to answer" option or offered a written response that participants could choose to leave blank. Although there were more females (75%,  $n=21$ ) than males (25%,  $n=7$ ), the race/ethnicity of the sample was similar to the university as a whole with 71% ( $n=20$ ) identifying as Hispanic/Latinx. There was also balanced representation from each college, between undergraduate and graduate students, and by age range. Table 1 provides the specific demographic information for each category and additional information on identified disabilities. We developed disability categories with guidance from recent literature (e.g., Mamboleo et al., 2020). The largest subgroup (35.7%,  $n=10$ ) identified multiple disabilities from

multiple categories. For example, one individual identified emotional or psychological conditions (i.e., post-traumatic stress disorder; PTSD), a hearing impairment, medical conditions (i.e., knee and back injuries), and a traumatic brain injury. The second group (25%,  $n=7$ ) identified various medical conditions, including Lupus, diabetes, seizure disorders, pregnancy, chronic regional pain syndrome, and knee, back, or shoulder injuries. The third group (17.9%,  $n=5$ ) identified various emotional or psychological conditions, including PTSD, schizophrenia, depression, bipolar disorder, and anxiety. The fourth group (14.3%,  $n=4$ ) identified a learning disability (LD), with some using the term dyslexia, and the fifth group (7.1%,  $n=2$ ) identified ADHD.

### **Researchers**

The first author participated in all aspects of the study. He is a white male with a background in special education. Two graduate student researchers assisted with specific components of the study. Both are Hispanic females. The second author participated in data analysis, assisting with qualitative coding. The third author participated in interviews and completed transcriptions of interview recordings. To reflect on our positionality, we had conversations about how our personal and academic backgrounds (e.g., special education, mental health counseling) might influence participants during the interview or the analysis of data. These conversations led us to decide to take a few minutes to build rapport with participants prior to asking the official interview questions, discussing our background and reminding them that we were unaffiliated with DS. We also decided to discuss differences of opinion during coding. For each interview excerpt, at each stage of the coding process, we came to a consensus on which code to apply, reflecting on our differences of opinion (Harry et al., 2005).

### **Interviews**

Over the course of a month, each participant completed an individual semi-structured interview (Creswell, 2014). These interviews lasted between 25 min and 50 min. The first author conducted all interviews with a graduate student present at most, except those that took place on weekends or nights. Both took detailed notes throughout the interview and discussed them afterward. All participants had the option of completing the interview in English or Spanish and with or without a recording device. However, all chose English and allowed recording.

The researcher-developed semi-structured interview questions guided the conversation around the participant's (a) personal and educational back-

**Table 1***Participant Demographics*

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

ground, (b) development of self-advocacy, and (c) role of social support. Table 2 lists the guiding questions. First, participants discussed their backgrounds and their experiences learning about their disability and interacting with disability-related and general student services. Second, participants evaluated what self-advocacy meant to them and how they developed the ability to self-advocate over time. Third, participants described their social support, how it developed over time, and how it contributed to or deterred their ability to self-advocate. We asked follow-up questions throughout the interview to define key terms and obtain additional concrete details.

After the completion of the interview, we gave participants a gift card via email and uploaded the recording to Otter.ai, an online transcription service. Then, we listened to all recordings, corrected errors in the preliminary transcription, and removed personally identifiable information (e.g., names, specific places or programs, unique descriptions). Finally, we emailed a copy of the transcription to each participant for a member check. Here participants had the opportunity to review their responses, make changes, or request the removal of personally identifiable information that was overlooked. No participants requested major changes to their responses, but many identified a few minor changes to wording. Two participants volunteered to review findings after the analysis of data to ensure the appropriateness of identified themes, student descriptions, and selected quotations.

### Analysis

After the completion of member checks, we uploaded the deidentified transcripts to Dedoose, an online qualitative coding platform. We followed a multi-stage team coding process, beginning with a priori coding of the four components of self-advocacy developed by Test et al. (2005). The first author began by line-by-line coding all excerpts (i.e., individual statements in interview transcripts that expressed a complete idea) into knowledge of self, knowledge of rights, communication, and leadership. Given the overlap between categories, some excerpts had two codes (e.g., knowledge of self and communication). Then, to provide researcher triangulation, the graduate student re-coded all unique ideas, using the test (i.e., interrater reliability) function in Dedoose. This generates a report of all similarities and differences in coding. Instead of reporting interrater reliability, we decided to discuss all differences and come to a consensus on the appropriate code(s). After a complete review, we coded 126 excerpts as knowledge of self, 98 excerpts as knowledge of rights, 167 excerpts as communication, and 52 excerpts as leadership.

For the next stage, we identified themes through process coding (Saldaña, 2016). With this technique, we coded individual excerpts from each self-advocacy category with a phrase that represented the action taking place. For example, we coded the excerpt, “One of my classes last semester, I had to do a paper and PowerPoint on accommodations. So, that’s where I learned a lot about what actual [DS] was, and what was actually available and who all qualified,” as *learning about accommodations and DS in a college course*. With this technique, we coded all excerpts to consensus. After process coding, we discussed patterns and merged similar codes. Following the same example, we identified a pattern of codes related to students whose initial experiences learning about rights came in college. Then, we merged similar patterns and identified a broader theme, *gaining initial information about rights through research or knowledgeable individuals*. Using this process, we identified three themes for each self-advocacy category for a total of 12 themes.

## Findings

### Knowledge of Self

Knowledge of self is defined as an individual’s knowledge of their disability, including their strengths, preferences, interests, and needs (Test et al., 2005). This knowledge is part of an essential first step in the process of developing self-advocacy. One student, Maya, an undergraduate with an undisclosed health condition, described its importance, saying, “To me, self-advocacy is being able to find yourself, then, doing whatever you need to succeed in your classes or with life.” The process of finding oneself, or developing knowledge of self, is influenced by a student’s personal characteristics, past experiences, and support system. In this study, students became well-versed in their disability and developed self-management skills at various stages in their lives. However, a few common themes emerged from the data, clarifying this process.

### *Negotiating Stigma and the Decision to Seek Support*

In developing knowledge of self, students often described an arduous process of negotiating stigma and deciding whether or not to seek support. Most students experienced an ongoing struggle with stigma at some point in their journey toward acceptance, including before they received their initial evaluation and after they received services in college. For example, Jose, a graduate student with schizophrenia, described his negotiation with internalized stigma prior to receiving services.

**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 definition if needed)?</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 definition if needed)?</p> <p>Who are your key social supports? How have they changed over time?</p> <p>How have these specific individuals or groups supported you?</p>
Combined	<p>How have specific individuals or groups influenced your ability to self-advocate?</p> <p>What types of support were most influential for your development of self-advocacy?</p>

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."

### ***Becoming Self-Aware and Empowered through Research and Reflection***

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.

### ***Drawing on Social Support Throughout Process of Becoming Self-Aware***

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, Adriana first addressed her bipolar disorder with a professor, who became a close advisor and friend. She said, "[The professor helped me in] understanding that, you know, this is not in your head. This is real." With this type of support, students were able to reach out to counselors or other professionals, who guided further self-reflection and the development of self-management strategies. Along with formal support, many students expressed that a supportive family environment, or other informal supports, contributed to their ability to gain knowledge of self. For example, Lili-ana, an undergraduate with ADHD, attributed her development of self-esteem to her parents.

Starting off young, my parents had always integrated in us the importance of standing up for yourself and taking care of yourself and taking care of others as well. So, having that at a young age really helped me to develop in a way that self-care matters.

Inversely, others reflected that their lack of support from informal sources contributed to a delay in gaining knowledge of self. In particular, Andrea, a graduate student, said that her negative interactions with others hindered her ability to self-reflect on her ADHD for years.

I think the lack of support in just understanding from peers and even from family early on is why it did take me so long to understand more about what my condition is and how best to be efficient. I think that kind of stunted my growth.

### **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.

#### ***Gaining Initial Information about Rights Through Research or Knowledgeable Individuals***

Most students expressed having limited knowledge of rights upon seeking services for the first time, gaining initial information from research or knowledgeable individuals. At first, students often did not know that they could receive services for emotional or psychological conditions or temporary disabilities, such as pregnancy or injuries. Reflecting on her initial lack of knowledge, Sharon, an undergraduate, said, "I didn't think that I was really covered because pregnancy is not a disability...I looked online first, I went to the [DS website], and it very clearly says that pregnancy is a temporary disability." Beyond doing independent research, students gained initial information about rights through knowledgeable individuals, including special educators, college professors, and DS staff. For instance, Hugo, an undergraduate with LD, learned about the process for requesting accommodations from attending special education meetings with a transition specialist in high school. Once in college, students tended to learn about their rights from professors, who shared information about DS in their syllabi or spoke individually with students they mentored. Others learned about their rights from individuals at DS, either by going to their office or hearing from them at events on campus. For example, Andrea described going to their office for the first time. She explained, "I walked in and was like, okay [name of person at DS], I don't really know what can request, what are the options, and so she spelled that out really well."

#### ***Navigating Rights Violations and Gaining Additional Knowledge***

Beyond initial information, students tended to gain additional knowledge of rights when navigating rights violations and inaccessibility. Although many students described mainly positive experiences, oth-

ers struggled with frequent resistance to accommodations, discrimination, and inaccessible contexts. For example, Allison reflected on a negative experience with a professor. She said, "He [professor] just completely told me that I would never be successful because I have a disability." She reported the incident to multiple channels (e.g., DS, department chair), but stated the professor did not face any consequences. Through negative experiences, students researched the nuances of the law and gained strategies to navigate difficult situations. Similarly, Javier, an undergraduate with multiple disabilities including a hearing impairment, described a situation where a professor refused to use a microphone connected to an assistive listening device during lectures. Even after reporting the incident, the professor continued to be noncompliant. In researching his rights, Javier reflected, "If someone really wanted to sue, they're breaking considerable laws...That's discrimination. They just don't care." In the community, students also gained additional knowledge and strategies to manage challenges to their rights. For example, students with service dogs, including Mark, Juliet, and Daniel, often became well-versed in policy due to frequent questions from others. To navigate these situations, Mark, a graduate student with multiple disabilities, said, "I carry a folder with me most of the time to show [dog's] paperwork, his training, and the federal laws."

#### ***Making Informed Decisions Based on In-Depth Knowledge of Rights***

Through gaining in-depth knowledge of rights, students made informed decisions about services and provided recommendations for systems improvement. For example, students who gained knowledge of DS policies could make informed decisions about their individualized situation. Andrea explained, "I request all the accommodations for all the classes just so they're there in case I decided I need them. I use less than half of what I'm actually granted." With experience, students also formed opinions about new policies and the limitations of current legal systems. Policy change suggestions included the need for additional accessible parking, more online course offerings, and increased flexibility in taking tests. Even with a detailed knowledge of rights, many students believed that they still had to be cautious about disclosing their disability due to a lack of enforcement, especially in the workplace. Often, students with emotional or psychological conditions expressed these concerns about accountability in the legal system. George explained his thoughts regarding limitations in current workplace policies.

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.

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.

#### ***Initiating Communication with Encouragement from Others***

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]

went to the office with me for the first time. She sat there while I filled out the forms

#### ***Developing Confidence and Preferences with Communication***

As students developed communication skills by interacting with formal and informal supports, they began to express confidence in their abilities and preferences. Confidence often came from positive experiences and practice. For example, Guadalupe attributed it to practice in her undergraduate studies. She said, "Once I got into graduate school, I was not afraid to advocate for myself and went straight to [DS] and was able to request the accommodations that I was needing." Over time, students also developed a wide range of preferences, from being very selective to being very open. Many felt that discussing disability was private. For example, Javier explained that he only brought up his PTSD when absolutely necessary, saying, "I tell the counseling department but it's on a need-to-know basis, right? I don't think anyone should disclose that information unless there's risk of life." In some cases, students were selective in their communication due to past negative experiences. For example, Maya chose not to disclose the name of her health condition to professors or peers.

I don't tell people [about disability] because some people have compassion, and some people say, "You are weak. You are a person who only wants to be a victim. You want more time to do assignments or you want this, and you want that."

Alternatively, many students stated that they began talking openly about their disability upon meeting others in similar situations or having positive experiences self-advocating. For example, Diana opened up about her experiences going to counseling to manage her depression and anxiety, saying, "I'm a big mental health advocate. So, I tried to normalize talking about those sorts of things."

#### ***Gaining Tactful Communication Strategies for Challenging Situations***

In facing challenging situations that required self-advocacy, students developed strategies for tactful communication, such as being proactive and persistent. Proactive communication included speaking to professors at the beginning of the semester or going to the DS office or another professional as soon as a new issue arose rather than waiting for an emergency. Persistent communication included reaching out to professors and DS multiple times, rather than just once, to ensure adequate services. For example,

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's really costly too, and it's horrible sometimes. It just seems like I'm fighting with the world. You have no idea how it is to constantly just tell someone [about disability and needs]." Facing challenges, students were forced to communicate with professors, department chairs, deans, and DS to receive appropriate services. Some had success resolving inaccessibility, while others continued to face barriers that did not seem to have solutions. For example, Justin explained that his specific department had a history of not following accommodations despite self-advocacy from students with disabilities. He said, "The teachers have been reported before to the higher ups and it does nothing except for make them mad at that student."

## Leadership

Leadership is defined as an individual's ability to advocate for others through individual or collective action (Test et al., 2005). Although all students in this study expressed knowledge of self, knowledge of rights, and communication, only some expressed interest in or experience with leadership. The students who discussed leadership tended to have the most confidence communicating their knowledge of self and rights with others. They were also the ones who expressed positive relationships with others, access to supportive communities, and time to participate in

organizations. Although leadership is most associated with advocating for others, students who expressed leadership said they benefited from it, too. The following sections describe themes related to the process of developing leadership.

### *Learning to Act as an Informal Support to Others*

Many students began their development of leadership by supporting those around them. Most started by assisting people that they knew such as family members and friends. For example, after becoming comfortable sharing her experiences with PTSD and depression with her sister, Gabriela began offering support to others in her family. She said, "People reach out, so I encourage them to get help. My mom started seeking therapy as well because of my sister and I advocating for her." Then, students discussed becoming leaders for people who they did not know well, including classmates and other students at DS. Mark, a veteran, wanted to help others in similar circumstances. He said, "Anytime I see a veteran, I always ask them if they're registered with [DS]...because if they have a disability, they qualify." Often by sharing their story, others came to them for support. For example, Alison made the decision to be a leader by telling her classmates about her accommodations and answering their questions about them.

I decided to be very vocal about needing those accommodations, and I've had multiple people in my class reach out to me and ask about the process of getting accommodations and how beneficial it was for me going and seeing counseling.

Others even decided to join DS and provide accommodations to give back. Sharon said, "I've helped other students. I've been a note taker, and I've done that for two or three of my classes."

### *Broadening Leadership Impact through Career Path*

Beyond helping family members, friends, and classmates, many students desired or enacted leadership through a career path. To help others with disabilities or similar backgrounds, many students sought careers in fields such as education, counseling, and health care. For example, Gabriela wanted to broaden her impact to help people going through health challenges.

Both my parents have struggled with their health their whole lives. It's difficult for them to have access to health care. I was like, "What if I could be someone who can provide that access to people like my parents?"

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 works differently.

Similarly, as a speech therapist, Guadalupe shared her disability with the children and parents she worked with, hoping to teach self-advocacy and be a positive role model.

I worked a lot with children with dyslexia. Something I was always pushing is that you're smart... it's okay to raise your hand. It's okay to tell the teacher to repeat what she said. It's okay to sit in the front...I tried to break those walls.

### ***Addressing Societal Issues Through Leadership in Organizations***

Lastly, through work in local, state, and national organizations, students developed the leadership skills to advocate for larger societal issues. Students volunteered with a variety of organizations related to their disability or other topics important to them. Through involvement in these groups, students promoted changes in policy and became leaders in their community. For example, Javier joined a veteran's organization to help support other veterans and address issues in the local government.

I joined a group, so it's kind of like a union, so to speak. So, we could address issues as a consensus rather than individually to kind of get more of a voice in the community and in the local government.

By joining advocacy groups, students were able to broaden their leadership efforts and connect with others to further develop their own self-advocacy skills. Juliet explained how involvement in a mental health organization helped her negotiate stigma at a personal and societal level.

The fact that I'm very involved with [mental health organization] at the state level is helping me with that stigma because I think that even unconsciously it's still affecting me, and I'm sometimes afraid of what people will think, in terms of other classmates or instructors, or even friends, but I try because I see that it's bigger than me.

## **Discussion**

Semi-structured interviews revealed the diverse perspectives of 28 college students with disabilities at an HSI. To address our first research question, our analysis revealed 12 process-oriented themes on the development of self-advocacy (i.e., knowledge of self, knowledge of rights, communication, leadership; Test et al., 2005). Most importantly, we identified processes associated with initial and more advanced self-advocacy development. Initial phases included gaining disability-awareness, learning about specific rights and policies, and developing communication skills through seeking an evaluation, disclosing one's disability to others, and requesting access to services. Advanced phases of self-advocacy development included gaining a sense of empowerment, learning the nuances of policies, and excelling in communication and leadership skills aimed at navigating complex situations, offering help to others, and advocating for improved systems. Our findings help contextualize self-advocacy, highlighting the way students learn and perform self-advocacy differently depending on their unique backgrounds and experiences (Trainor, 2017). Like Pfeifer et al. (2020), we found that agency and views on disability impacted self-advocacy development. Some students preferred gaining knowledge and skills independently, while others relied more on formal and informal supports. Similarly, some students felt comfortable discussing disability with others, while others were more private. By considering these contextual factors, practitioners can adapt current self-determination and self-advocacy programs (e.g., Ju et al., 2017; Rowe et al., 2021) to be more personalized and culturally responsive.

To address our second research question, we identified specific themes related to the influence of social support on self-advocacy development. Our findings extend prior research on the interconnectedness of self-advocacy, social support, college experiences, and postsecondary outcomes (Daly-Cano et al., 2015; Kimball et al., 2016; Lombardi et al., 2016). Confirming prior literature, our study found that students benefited from both formal and informal social support (Bromley et al., 2020; Stein et al., 2012). Early socialization from friends, family members, and educators tended to shape students' experiences learning self-advocacy (Daly-Cano et al., 2015; Kimball et al., 2016). This finding confirms the importance of early self-advocacy instruction (Rowe et al., 2021), especially for students who lack social support. For more advanced self-advocacy development, students benefited from engagement with various social networks (Kimball et al., 2016; Pfeifer et al., 2020; Stein et al., 2012). Having a diverse and comprehensive set

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 identified leadership as part of their self-advocacy development (Pfeifer et al., 2020; Test et al., 2005), many became leaders and worked as empowerment agents for others. They believed that helping members of their community and working with organizations to address societal issues was intertwined with their own self-advocacy development. These students saw self-advocacy as "bigger than me," blurring the distinction between self-advocacy and activism (Kimball et al., 2016). This finding strengthens the need to develop self-advocacy programs that incorporate authentic support and connections to social and political organizations on campus.

### **Implications for Practice**

Self-advocacy and self-determination are considered evidence-based predictors of postsecondary attainment for students with disabilities (Mazzotti et al., 2016). For secondary educators, Rowe et al. (2021) detailed multiple evidence- and research-based programs that are effective in increasing self-determination and self-advocacy skills (e.g., Self-Determined Learning Model of Instruction, Self-Advocacy Strategy, Take Charge curriculum). Specifically, to teach knowledge of rights and communication, we recommend that educators consider implementing programs, such as the Self-Directed IEP, that prepare students to lead formal special education meetings (Sanderson & Goldman, 2020). In our current study, students who attended special education and transition planning meetings in grade school expressed confidence in accessing DS in college. When implementing these programs, educators should collaborate with students' families and other key supports to identify cultural and community assets to leverage during the transition to postsecondary education (Achola & Greene, 2016).

For college students with disabilities, a literature review by Ju et al. (2017) found that the self-determination programs with the most research support included self-advocacy training models, the personal strengths program, and peer-based coaching services. Our findings support the use of these programs, as many students expressed benefitting from interactions with DS, professionals, and peers. Park and Boutelle (2009) found that peer-coaches provided students the encouragement needed to become autonomous. To implement such a program, DS can recruit students with disabilities, like many in our study, who possess leadership skills and a desire to advocate for others. DS can also encourage these students to collaborate with activist groups on campus to address stigmatization and other inequities facing individuals with disabilities (Kimball et al., 2016). However, many students in our study expressed feeling uncomfortable discussing their disability with peers and may benefit more from a professional-led or family-led approach. Achola and Greene (2016) described a person-family centered approach for assets-based and culturally responsive transition planning with students from culturally and linguistically diverse backgrounds. With such a model, professionals act as facilitators who convene a diverse team of formal and informal supports to determine how best to deliver services. For a person-family centered approach to self-advocacy in postsecondary settings, DS can develop first-year experiences, workshops, or support groups that incorporate students, their families, friends, and other key supports.

### **Limitations and Suggestions for Future Research**

Our findings are limited in several ways. First, although the sample included students with a diverse range of disabilities, it included few students with physical or sensory disabilities and no students with intellectual or developmental disabilities (e.g., autism spectrum disorder). Further research is necessary to better understand self-advocacy development for these students, especially students with intellectual or developmental disabilities who are attending college at increasing rates (Gilson et al., 2020). Our sample also skewed toward students identified with multiple categories or emotional or psychological conditions. We interviewed fewer students with LD or ADHD despite those categories being some of the most prevalent. Second, our findings are limited to students at a single HSI who were registered with DS. Although many students discussed their cultural and linguistic backgrounds, future research should specifically examine these influences on self-advocacy development. Furthermore, many students do not self-disclose their disability in college for vari-

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 with disabilities revealed process-oriented themes related to the development of self-advocacy. Findings detail the influence of social support in students' initial experiences self-advocating and later experiences learning more advanced knowledge and skills. By better understanding the unique experiences of college students with disabilities and the barriers they face, key stakeholders can design more responsive systems with increased accessibility and accountability. By promoting self-advocacy and reducing stigma, we can improve students' experiences in college and increase the likelihood of smooth adjustment, academic success, and overall positive outcomes.

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### About the Authors

Kristopher Yeager received his M.Ed. and Ph.D. in Special Education from The University of Nevada Las Vegas. His experience includes working as a high school special education teacher for the Clark County School District. He is currently an assistant professor at the University of Texas at El Paso in the Department of Counseling, Special Education, and Educational Psychology. His research interests include transition planning, social support, and qualitative methodologies. He can be reached by email at: [khyeager@utep.edu](mailto:khyeager@utep.edu).

Gabriela Alejandra Gandara received her B.A. in Psychology from the University of Texas at El Paso and is currently completing her M.S. in Mental Health Counseling at the same institution. Her experience includes working as a research assistant in the Department of Counseling, Special Education, and Educational Psychology. Her research interests include advocacy and social-emotional learning. She can be reached by email at: [gagandara@miners.utep.edu](mailto:gagandara@miners.utep.edu).

Cecilia Martinez received her M.Ed. in Special Education from the University of Texas at El Paso. Her experience includes working as a research assistant in the Department of Counseling, Special Education, and Educational Psychology and working as a special education teacher in Portland, Oregon. Her research interests include transition planning and self-advocacy. She can be reached by email at: [cmartinez65@miners.utep.edu](mailto:cmartinez65@miners.utep.edu).