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"It's a Constant Fight:"
Experiences of College Students with Disabilities

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Abstract

Despite the increase in students with disabilities attending college, the graduation rates of these students consistently lag behind their peers without disabilities. Although services provided by college disability service offices are designed to prevent discrimination and support student success, a limited body of research documents the effectiveness of services delivered to students with disabilities in college. Further, little is known about the perspectives of students with disabilities in the U.S., including in-depth qualitative research among diverse students. The purpose of this qualitative study was to explore the perceptions and experiences of eight college students with disabilities. Participants described disempowering experiences, empowering experiences, reported information about the impact of their families, and provided recommendations for stakeholders to better support individuals with disabilities. Implications for practice and future research are reported.

Keywords: college, disability, services, barriers, qualitative

The rate of students with disabilities attending college in the U.S. continues to rise (Smith, 2007), with some researchers estimating the number of students tripling or even quadrupling over the past two decades (Barnard-Brak, Lechtenberger, & Lan, 2010; Brown & DiGaldo, 2011). This rise may be due to several factors, including effective transition planning in high school (Morningstar & Mazzotti, 2014); parental education (Wang, Chang, & Lew, 2009); external motivation (e.g., enhanced job prospects; Reed, Kennett, & Emond, 2015); and greater rates of disclosure among individuals with disabilities attending college (Vickerman & Blundell, 2010). Despite this increase in students with disabilities attending college, the graduation rates of these students consistently lag behind their peers without disabilities (Anastopoulos & King, 2015; Grogan, 2015). For students with disabilities, postsecondary degree completion rates range from 29% at four-year universities, 30% at two-year colleges, and 55% at vocational or technical schools, with no significant differences in completion rates by race or ethnicity, gender, disability category, or parents' household income (Sanford et al., 2011).

Section 504 of the Rehabilitation Act (1973) aims to support college students with disabilities through disability service offices located on campuses. These offices provide services and supports such as extended time to complete assignments, extended deadlines to receive a degree, course substitutions, instructional adaptations, use of tape recorders, audio texts, interpreters, and adapted classroom equipment (34 C.F.R. Part 104). However, students must disclose their disability and maintain an up-to-date evaluation in order to receive these services (Van Hees, Moyson, & Roeyers, 2014). Further, although these services are designed to prevent discrimination and support student success, a limited body of research documents the effectiveness of services delivered to students with disabilities in college (Gelbar, Smith, & Reichow, 2014; Grogan, 2015). Moreover, additional barriers, including (a) a lack of preparation for college in high school (Francis, Duke, Brigham, & Demetro, 2018);

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(b) limited student understanding of the nature of their disability and needs (Anastopoulos & King, 2015); (c) executive functioning needs (Cai & Richdale, 2016); (e) social and communication needs (Cai & Richdale, 2016); (e) mental health needs (Anastopoulos & King, 2015; Cai & Richdale, 2016); (f) challenges adjusting to change and unstructured environments (Wenzel & Rowley, 2010); (g) student hesitancy to advocate or disclose their disability in order to receive support (Burgstahler & Russon-Gleicher, 2015); and (h) college faculty uncertainty about how to support the needs of students with disabilities (Barnard-Brak et al., 2010; Dipeolu, Storlie, & Johnson, 2015; Odom & Wong, 2015) stymie the progress and success of students with disabilities in college.

Research demonstrates college students with disabilities reporting struggling with organization and assignment management as well as time management and setting a daily schedule (Van Hees et al., 2014). Students have also reported feeling overwhelmed, anxious, depressed, lonely, and tired and that they frequently procrastinated on assignments because they had no idea where to start (Sayman, 2015). As a result of these experiences, Van Hees and colleagues (2014) reported that students indicated that they would have benefited from a transition coach who could monitor and support their activities in choice making, study skills, daily and vocational organization and skills, clarifying ambiguities, and interacting socially and could provide feedback on issues and advice.

Although research documents general barriers experienced by college students with disabilities, little is known about the in-depth perspectives of students with disabilities in the U.S. For example, few researchers have investigated the experiences of transitioning into college (Anderson & Butt, 2017) and participants included in studies about college students with disabilities are not representative of the diverse population of students with disabilities attending college, including the number undergraduate and graduate students, and students of varying genders, ages, and disability types (Accardo, Kuder, & Woodruff, 2018; Anderson & Butt, 2017; Francis et al., 2018; Kendall, 2016). Further, the limited body of research that has studied the perceptions of college students with disabilities does not report their perceptions of family involvement (Francis et al., 2018) and lacks in-depth qualitative analysis (Reed et al., 2015).

This lack of information hinders an understanding of how to maximize positive college experiences and outcomes for students with disabilities. Therefore, the purpose of this study is to explore the perceptions and experiences of college students with disabilities, including their preparation for college. Three primary research questions guided this work: (a) How do participants describe their preparation for college? (b) How do participants describe their experiences in college? and (c) What recommendations to participants have to support the success of students with disabilities in college?

Method

The principal investigators (i.e., two special education faculty members) used convenience sampling techniques (Maxwell, 2005) to recruit participants for this study. The principal investigators recruited participants through the distribution of a researcher-developed online survey to college students with disabilities registered with the disability service office located at a large, public university in the mid-Atlantic region of the U.S. (Francis et al., 2018). Survey participants were overwhelmingly White/Caucasian (67%), female (63%), spoke English as their first language (93%), and reported their age between 18 and 24 years (70%). This survey included 33 questions related to (a) basic demographic information, (b) the degree to which they felt prepared to enter college, (c) services received at the university, (d) perceptions of university services, (e) suggestions for improving services, and (f) perceptions of family involvement in college. The survey also offered an opportunity for participants to provide contact information to participate in a follow-up interview about their experiences. Of the 109 participants who agreed to participate in the survey, 23 individuals provided their name and preferred email address to engage in a follow-up interview. One principal investigator attempted to contact the 23 individuals a maximum of three times over three weeks via email to schedule an interview. During this time, one email bounced back as invalid, 13 individuals did not respond, one individual indicated that they were no longer able to participate, and eight individuals scheduled interviews.

Participants

According to the demographic questions completed by participants, over 60% of participants identified as female (*n*=5) and White/Caucasian (*n*=5). All but one participant reported speaking English in their home. Six of the eight participants lived off campus with their families or in apartments located near the university. Participant ages ranged from 18 to sixty years old and the number of years in college ranged from undergraduate students (*n*=3) with less than one year spent in college to graduate students (*n*=5) with five or more years in college. Participants self-reported primary disabilities (e.g., mental health, specific learning disabilities, hearing impairment, visual impairment) and primary support needs (e.g., self-management, academic, vocational support) among participants reported varied. Table 1 displays participant demographic information.

Data Collection

The principal investigators conducted one interview in-person, four over the phone, and three via Skype or Facetime, depending on participant preference and availability. The investigators conducted interviews in a private room at the university with a noise-canceling machine placed outside of the door to protect participant privacy.

The principal investigator who facilitated interviews began by explaining the purpose of the study and related risks and benefits and obtained written informed consent, including participant permission to record the interviews, prior to interviewing. One investigator facilitated interviews, while the second recorded field notes and asked follow-up questions, as appropriate. All interviews were conducted in spoken English, as no participants indicated needing accommodations to participate. The investigators used a semi-structured protocol (Merriam, 2009) developed from previous research on the experiences of college students with disabilities (Francis et al., 2018; Francis & Reed, 2019). The protocol included questions related to (a) basic information about the participants (e.g., “Can you tell us a little bit about yourself?”); (b) experiences in high school (e.g., “Tell us about your experiences in high school.” “What supports, classes, or other experiences helped prepare you for college?”); (c) experiences in college (e.g., “Talk to us about when you started college.” “What supports have been the most or least helpful?”); and (d) recommendations to facilitate student success (e.g., “Pretend we are going to teach professors and staff at [University] how to support students with disabilities in college. What should we teach them?” “Pretend you’re in front of a group of new students. What advice do you have for students going to college for the first time?”). If participants discussed their families during interviews, we also asked probing questions about the nature of family involvement and recommendations for families to prepare individuals with disabilities for college (e.g., “Pretend that we are going to teach parents what to do when their children go to college. What should we teach them?).

Data Analysis

A professional transcriptionist transcribed all interviews. The principal investigators de-identified transcripts and then collaborated with a research assistant to read through all transcripts while listening to the audio recordings to ensure transcription accuracy (Creswell, 2009). The principal investigators assembled an analysis team consisting of four individuals (the two principal investigators and two graduate research assistants) with expertise in disability, education, support services, and higher education to begin the analysis process. The analysis team began with the principal investigators describing the purpose of the study, IRB requirements, and open-coding procedures to ensure a consistent conceptualization of the process. Next, each team member independently read and hand-coded a single transcript to determine keywords and descriptive categories represented in the data. The team then debriefed to identify similarities and differences among the open codes and developed an initial codebook based on this discussion. Using the initial codebook as a guide, the team then hand-coded another transcript and met again to discuss primary and subthemes, identify unique or irrelevant topics, and develop rich descriptions of themes. This process resulted in a second version of the codebook. Finally, the team used the same hand-coding and debriefing process with another transcript, which resulted in a third and finalized version of the codebook. The primary investigators used the finalized codebook and NVivo qualitative software to perform basic interpretative qualitative analysis of the data by recoding all of the transcripts with the finalized codes (Merriam, 2009). The primary investigators also continued to meet weekly until all data were analyzed to ensure consistency of analysis procedures.

Trustworthiness

The analysis team employed numerous measures to ensure the credibility of data analysis. First, the principal investigators attempted to ensure trustworthiness during interviews by encouraging participants to command the discussion through the use of open-ended questions and prompts, recording interviews to gather precise information, and debriefing and composing researcher memos immediately after interviews (Wolcott, 1990). Second, the principal investigators used field notes to conduct informal member checks throughout interviews by reviewing major ideas and events with participants and inviting them to correct or expand on information. They also conducted more formal member checks with participants at the end of each interview by reviewing key themes and concepts. Third, the principal investigators compared written transcripts to original interview recordings to ensure accuracy. Fourth, the analysis team was comprised of four individuals with interests and expertise in the nature of this research. The first principal investigator was a faculty member in the department of special education, a former special education teacher, an administrator for a college program for individuals with disabilities, and a sibling of a brother with disabilities. The second principal investigator was a faculty member in the department of special education, a former special education teacher, and former special education advocate. The first graduate research assistant was a mental health social worker studying higher education policies and practices and the second graduate research assistant was a former high school administrator, special education teacher, and parent of an adolescent and young adult with disabilities. These diverse experiences lend to the trustworthiness of our analysis by providing our team with a unique perspective that blends personal and professional experiences. Fourth, the analysis team met weekly to review and discuss interpretations of data and consider researcher bias in the analysis (Patton, 2002).

Results

While discussing their experiences prior to and in college, participants described feeling disempowered (e.g., negative experiences; feeling unmotivated, disrespected, isolated, less worthy, unvalidated) or empowered (e.g., positive experiences; feeling encouraged, satisfied, proud, respected, accomplished). They also reported information about the impact of their families and provided recommendations for stakeholders to better support individuals with disabilities.

Disempowerment

Five key interrelated subthemes emerged under disempowerment: (a) discouragement, (b) debasement, (c) insecurity, (d) isolation, and (e) repeated cycles of disempowerment.

Discouragement. Discouragement emerged as a key theme among all participants that resulted in them feeling "disempowered." Several participants such as Nora, Lydia, and Rodney described how not receiving a disability diagnosis until late in high school or in college resulted in them feeling discouraged throughout their educational journey. As Nora noted:

> They knew something was wrong but they…put me into a regular 3rd grade class and then stuck me in the back of the room and nobody helped me. So probably some of my difficulties may have come from a lack of proper education because I wasn't helped.

Shivani also described how an earlier diagnosis might have prevented unnecessary distress through the provision of appropriate accommodations: "I wrote this extra paper three or four times and I received the same grade each time. It was awful. And there was no light at the end of the tunnel. It was awful. I'd spend nights writing essays and I'd still get B's and C's on them."

Many participants also found educators who lacked knowledge about disabilities or basic accommodations discouraging. For example, Landon indicated that one of his high school teachers "basically told me that I should learn my colors" when Landon attempted to explain the impact of his colorblindness. Rûna and Delmy, who both have hearing loss, lamented when educators would "pop in a video" without subtitles, "over-exaggerate" their speech, or "turn their backs" while lecturing, which made lip-reading impossible and difficult to gather meaningful information during class. Nora also described a discouraging experience when seeking help at the writing center in college:

> I was excited. Somebody that understands disabilities and I'm going to go in there and show them my work to get feedback on how I can process this correctly and how I can get my thoughts out and all that stuff…The only thing she did for me was show me a web and I started crying because I was like once again, I have been disappointed. How can you advertise writing for disabilities and that person not be somebody who specializes in that?

Other participants described accessing different types of services (e.g., support groups, academic accommodations, audiobooks), but noted that these services "just didn't work" or even perpetuated "a counter-productive negative cycle" of failure. This was especially true for participants with mental health needs. Tae described the failure of high schools and universities to provide adequate mental health support, especially to students in crisis: "A lot of people they are feeling on edge and then they don't get the psychological support they need right away. They have to make an appointment or whatever." Tae also elaborated on the negative impact of ineffective mental health services in the community: "When you get admitted as an in-patient in the hospital, they pretty much just overdose you with medications and send you off into the real world."

Participants indicated that a lack of faculty training and support staff offering services to students on a one-size-fits-all basis as being particularly troubling. For example, Nora lamented a "worthless" remedial math course she took at a community college prior to attending her current university: "Once or twice a week you went to class with the teacher sitting at the front while you worked on the computer. But nobody actually taught you anything." Shivani described how she "wanted to collapse" after finding out that a professor did not allow peer support for homework: "I got a couple of friends in that class and I wanted to do my homework with them but then she was like 'no collaboration.' With disabilities, that's how you learn-you can't do everything by yourself." Further, while she appreciated the remote captionist services provided in college, Rûna indicated that this accommodation was not well-suited in graduate courses because of the amount of group work. Rûna also noted that some captionists or typists who supported her in college were unfamiliar with course content, which resulted in gross miscommunication and confusion, such as when one typist typed "terrorists" instead of "tariffs."

Professionals lacking knowledge and ineffective services and supports resulted in participants feeling discouraged and unprepared to excel in school. Participants felt unprepared when their disabilities were "normalized too much" in high school or when they were given assignments below what was expected for their same-age peers. As Delmy put it:

> In high school I wasn't really prepared for college…the amount of papers I had to write was more than what I was used to because I'd never had to write so many papers…The classes were more advanced than what I was used to.

Rûna had a similar realization once she entered college: "Like I thought I was up *here* and actually I'm down *here* and I need some assistance…For students with disabilities…you think that you're on the same playing field and that's not reality." Several participants, including Lydia, Delmy, Nora, and Rûna also wished, as Lydia stated, they "had known the processes and different benefits" they could have received in high school and college. Participants felt thrust into the "real world" after graduating high school without a solid understanding of service eligibility, the cost of disability testing and assistive technology, and opportunities for college scholarships or other forms of support.

Debasement. Feeling debased and discredited was another predominate theme that resulted in participants feeling disempowered. Participants consistently described educators "not believing" they had disabilities, but rather maintaining that participants were not "studying," "trying hard enough," or "paying attention" in class. Nora recounted feeling "completly shocked" when attempting to secure accommodations with the disability service office in college:

> When I first was diagnosed and I brought in my paperwork to get accommodations, the first person I met with in the disability office literally said to me that she would never have diagnosed me with disabilities. She said, "I would never have diagnosed you with any disabilities. I think it's just because it's been a while since you've been in school."

Other participants also found that, as Rûna said, "it was very much like a student doesn't have a disability until you prove you do" in college. For example, Landon "had to basically show" a professor that he was unable to visually discriminate between colors in a chemistry lab before he was allowed to work with a partner (despite this being listed as an accommodation on his disability service office form). Participants described other instances of professors "refusing to accommodate" their required accommodations such providing PowerPoints, lecture notes, or extended time because they did not believe participants required the accommodations or because they didn't "want people stealing" intellectual property included in lecture notes. In general, participants believed that the disability service office should have been "standing up" and "advocating" for them in these instances of being discredited because "it's their job" and "it's the law."

Insecurity. Participants reported feeling "depressed," "inadequate," and generally insecure when comparing themselves to their peers without disabilities. For example, as a child Rodney "noticed that a lot of [his] classmates didn't have the same kind of difficulty" he experienced with writing or that his peers received higher scores on assignments, despite him putting in "twice the effort." Shivani speculated that some of her insecurities stemmed from growing up in an "Indian household" or within "the Asian community" because, despite all of her academic efforts and achievements, she was still considered "an underachiever" compared to her family and friends from similar cultural backgrounds. In the same vein, participants reported feeling intimated and insecure when transitioning to college for numerous reasons, including taking courses with "over 70 or 80 students," asking professors for help, and coping with enhanced expectations and challenging coursework. Several participants, including Shivani, Tae, and Nora purposefully selected majors based on their insecurities or concerns related to their disabilities (e.g., "I would have stayed in elementary education….

However, I didn’t feel that I was able to teach upper grades, 4th, 5th, 6th, because of my disabilities…because I struggled.”).

Regrettably, participants also spoke about often feeling embarrassed or ashamed when professionals disclosed their disabilities without their consent (e.g., assigning participants to specific classes or spaces in rooms, assigning participants to work with specific workgroups, making fun of participant mistakes or misunderstandings in front of others). Nora summarized how many participants characterized the negative long-term influence of these experiences:

> It's so much more intense because you already play in your head the negatives…It's harder to move on. I still play in my head the experiences as a child and what I felt growing up. Little things that happened and even in my math [class]- the [professor] rearranged the seats and put me next to students that were really good in math. I just broke down and cried because I literally was that 3rd grader all over again, put in the back of the room.

Isolation. Feeling isolated emerged as another factor contributing to disempowerment. Part of the isolation experience for participants was related to reconciling what it meant to have a disability and how disability influenced their identity. Some participants, such as Tae, felt uncertainty and confusion once they were diagnosed (e.g., “I didn't really understand it at the time”), while others such as Rûna recalled “very vivid memories” of being diagnosed: “My mom is sobbing. And I am asking, ‘Am I dying?’ And instead I get these purple hearing aids.” In high school Rûna also became even more concerned about the nature of her disability:

> All of the students that had hearing aids...most of them were mentally retarded. So then it's kind of like wait - so am I like THEM? And you're kind of scared to ask questions and I didn't know if this was like by being hearing impaired it could lead to something else.

Delmy had a similar experience when she was re-evaluated and diagnosed with autism in addition to a hearing impairment in college:

> I will say I broke down because I was very upset and I didn't know why they were telling me when I was already in my 20's and I'm just like why is this happening now? And I have a brother who's Autistic. He's two years younger than me and he can't speak for himself. And when they told me that I was thinking am I just like him?

Feeling disconnected or isolated from family as a result of their disability also influenced participant isolation. Rûna described feeling like a “burden” on her family because “they look so depressed and so sad… they feel bad for their child. They still carry this stigma” of disability:

> My parents are still very much learning all about what America is. And to them having a child who's disabled from their frame of understanding is God's punishing us. We did something wrong- any person with disabilities, in most of the Middle East, they keep their child home. Whether you're Blind, you're Deaf, you're Autistic - they just - hidden is kind of the way they go.

Shivani shared similar experiences about her family: “My mom - even when I started to ask for help, she had this negative stigmatism like you're not crazy! You don't have any problems!” Tae also described how “the Asian gender/race thing” left his family “really shocked” when he was diagnosed with bipolar.

Rûna not only felt isolated from her family based on their strong reaction to her diagnosis, but also because she was “mainstreamed” in school: “No one in my elementary school had hearing aids or was Deaf or hard-of-hearing. Middle school: no one.” In fact, Rûna mentioned that “I didn't meet another hearing impaired 20-something until I was 21, so I have been completely out of any community or network of people who have a similar disability to myself.” This resulted in Rûna feeling isolated from the hearing community because she’s “different” and also unsure if she “would be accepted in the Deaf and hard-of-hearing community.”

Repeated cycles of disempowerment. Participants used numerous terms and phrases when describing “the cycle” of “disempowerment” that emphasized the ongoing and cyclical nature of their experiences (e.g., “It's just kind of like one wall after another and it's never ending.” “If I didn't advocate for myself and allowed once again to be disempowered.” “It's a constant fight. And it always happens. Even today. It happens all the time.”). Multiple factors contributed to the continued cycle of disempowerment, including those previously discussed in this section. For example, cultural stigma and discrimination perpetuated cycles of disempowerment. In particular, Rûna, Shivani, and Tae described the ways in which disability is stigmatized in Middle Eastern and Asian cultures. These participants described how friends and families in their community “don’t talk about” disabilities or felt “scared” about disabilities. On another note, Rûna described how her college peers assumed she was a "spoiled, absorbed, student from some rich country [who] hired people to come takes notes for me" based on her ethnicity when they saw the disability service office-appointed captionist supporting her in class.

Participants, especially Nora, also talked about the disempowering impact of observing and experiencing low expectations of other students in schools. As a substitute teacher in an elementary school, Nora recalled several examples of educators talking negatively about children (e.g., "I can't believe she is so [academically] low") right "in front" of students. She also observed educators purposefully humiliating students with disabilities in class by using negative body language (e.g., ignoring student questions, turning their backs on students), physically isolating students in classrooms, and asking students to answer complicated questions in front of their peers. Observing these acts of humiliation and low expectations in schools activated strong feelings of disempowerment based on her own negative experiences in school: "it doesn't matter how old you are. We still want to feel safe [in schools]."

Finally, participants portrayed stigma and discrimination in the workplace as perpetuating disempowerment. Participants described various examples of discrimination on the job, including having "disabilities you can't see," human resources "protecting institutions, not people" in instances of discrimination, and supervisors accusing individuals with disabilities of being "lazy," "not trying hard enough, or being "too social." Other forms of discrimination related to age, gender, and race/ethnicity were discussed by several participants, including Rûna:

> You're a young person, female, minority, and a disability, right?... For a lot of job apps I don't want to say that I'm disabled. That's going to hurt me. Or is it going to help me? Do they have to have a quota?

Rûna also lamented the "bystander" effect of coworkers allowing discrimination to occur and the also consequences of "speaking up" and being "whistle blower" who reports acts of discrimination.

Empowerment

Participants also described instances in which they felt empowered and successful. Five key interrelated subthemes emerged under empowerment: (a) diagnosis, (b) effective supports, (c) family support, (d) resilience, and (e) advocacy.

Diagnosis. Although participants sometimes found their disability challenging, instances of self-awareness, understanding, and acceptance after receiving a diagnosis or understanding their disability also permeated interviews as a means of empowerment. Several participants, including Delmy described "starting to understand" themselves better after receiving a disability diagnosis: "Now I can tell people that I do have [autism]. This is me." Similarly, Nora described feeling validated after receiving a diagnosis: "I cried because I was like, I'm not stupid!" Participants also described becoming better self-advocates as they became "more comfortable" with their "disability" and "realized" that they are "more capable" than they once believed. Better understanding the nature of their disability also enabled participants to "do research" on effective strategies, as well as deeply reflect on ways in which they "survived" in the past. As Nora noted, "When I got diagnosed at first I didn't really talk about it. But then I don't know, I felt like I'm not ashamed of it. I'm not ashamed of my disabilities and I'm not afraid to tell people."

Effective supports. Just as ineffective supports and services resulted in disempowerment, participants felt empowered once they received effective and appropriate supports at school (e.g., extended time for texts and assignments, quiet testing centers, breaks during class, captionists). Delmy, Rodney, and Tae specified how attending community college helped them prepare for a four-year university by introducing them to services they did not receive in high school and by providing valuable mentoring support (e.g., explaining the differences between high school and college, suggesting which courses to take, proposing self-regulation and organization strategies). Other supports such as priority registration and more individualized academic or mental health services (e.g., take-home tests, posting recorded lectures and course materials online, "therapy once a week") also empowered participants once they entered the four-year university where this study took place. Both Shivani and Nora described how helpful it was when educators provided "genuine support" by taking time to "point out patterns" of mistakes and "make a conscious effort" to help them learn how to correct mistakes.

Interestingly, although participants found specific services and accommodations empowering, they determined that educators "who went beyond the accommodations," and were "caring," "warm," "fun," and "understanding" provided even greater degrees of support and long-term empowerment. Examples of these impactful educators included Lydia's experiences with her "supportive" and "nice" Latin teacher in high school with whom she often ate lunch. Shivani also noted the importance of "lov[ing] teachers who actually try to have a relationship with the student" or "at least acknowledge" when students are trying. Similarly, Nora highlighted the influence of educators who told her she was "capable" and "pushed her" to reach goals and achieve milestones.

Family support. Participants reported family members (e.g., parents, grandparents, spouses, siblings, children) providing various forms of financial, academic, and emotional support. For example, Shivani indicated that her family "has my back" and Tae said that his family helps him "get through the day." Other participants such as Rodney described how his spouse encouraged him to "get off [his] ass" and pursue higher education and Nora's daughters insisted that it would be "empowering" for her to "speak up [and] take back her power" and advocate for herself and other students with disabilities at the university and her workplace. Participants' families also supported their "dream of going to college" by providing tutoring support, "pushing" them to do their best, and helping them with assignments. In addition, family members provided participants information about disability services at college (e.g., "the disability center-my mom found out about it. I had no idea it existed") and served as a "career adviser." Finally, Shivani explained how her father helped her "set boundaries" with her other family members in order to reduce the amount of "control" they maintained over her life (e.g., "If I want to go to a friend's - if I want to go to the mall with friends, [mom's] like who, what, when, where, why, how? Are your friends driving? No. Let me drive you.").

Resilience. Participants reported numerous resilience strategies, or strategies used to recover from frustrating or wearisome experiences, that made them feel "stronger" as a result of working through trying experiences. One example included associating with "cultural clubs" or other "groups of people to hang out with" to provide moral, social, and emotional support. Participants also recalled "coping" with stigma or other disability-related challenges by "researching" and trying out different approaches to support their needs, using assistive technology or other "mechanisms" as forms of support, asking for help from peers, and "making a few people laugh… in the meantime."

Advocacy. Participants described many ways in which they advocated for themselves. For example, participants "took the initiative to go" to professors and describe their needs and accommodations, including attempting "to break down" how they learn and process information for professors, because, as Rûna noted, "I know if I don't advocate for myself nobody else will. That's the reality, right?" Participants also described coming prepared with their disability service office-issued accommodations form and other "proof" of their disabilities. Rûna described how she explained her hearing loss and needed accommodations: "I have my audiology exam on my desktop. So I explain it to [professors]–like all of this I can't hear. With the hearing aid it helps this much." Participants also found it helpful to describe the consequences of not receiving appropriate accommodations when advocating for themselves such as missing or misinterpreting vital information on the job or in class.

In addition, participants described empowering instances of advocating for others. For example, when asked why they decided to participate in this study, all participants indicated that they wanted to help other students learn about resources and supports, just like they needed when they were "starting out" in college. Participants described ways in which they advocated for the disability community, such as "let[ting] people try on hearing aids because they just don't know…that hearing aids don't give hearing, they just amplify everything" or discussing how to appropriately interact with or support individuals with disabilities among their peers and coworkers.

Recommendations

Participants made recommendations for (a) education systems, (b) professionals, (c) families, and (d) students with disabilities.

Education system recommendations. Participants called for education reform that more effectively prepares students with disabilities for "real life," including more thoughtful considerations for inclusion and information and resource sharing. Despite feeling isolated from being "mainstreaming" throughout her educational career, Rûna discussed the challenges and importance of thoughtfully considering inclusion: "Apparently now [County] sends all hearing impaired students to one specialized school. Which I think THAT is not the right way either. It shouldn't be two polar extremes, right?" Many participants also suggested that secondary schools take more systematic steps to better inform immigrant families of available resources within and outside of the school system to help students "prepare better" for college.

Although participants acknowledged an increasing acceptance of depression and other mental health needs in society, they expressed a need for education systems to consider "social/emotional" development as "the #1 focus" in school systems to maximize success in school and after graduation. Participants suggested that needed supports and services, especially those related to social and emotional support be available to all students, including those with "undiagnosed mental health issues." However, participants also noted that school professionals are often at "max capacity" and need decreased "caseload" sizes and ongoing "specialized" training in providing individualized supports. Participants called for "more education of teachers throughout elementary school through high school" about "what disabilities exist," how to help recognize disabilities, what accommodations, modifications, and assistive technology exist to support students, and how to "better understand the different neurological differences between people with learning disabilities and mental illnesses." Participants noted that this type of training would help teachers better support all students, thus preventing students having "to fail something before [getting] recommended" for disability services.

In college, Shivani recommended that there should "two seminars: one for parents and one for kids so that the kids learn that they need to be independent and make sure that they have the resources available and tell the same thing to the parents but in a different seminar." Multiple participants also recommended that colleges create more robust peer support groups or "platforms" "for those who are open about their disability to have other students reach out to them." Some participants indicated that this would be helpful for social and academic support, while others suggested that they would like a peer group of other people who have disabilities with whom they can "relate" to turn to for emotional support, especially during "stressful" times. Shivani also recommended the creation of groups of "alumni" college students with disabilities to "create communication with [new college students with disabilities] because they've been through it."

Professional recommendations. First and foremost, participants recommended that professionals "really stress the importance of respect for children in the school system" by making students "feel safe," "validating" students, "standing by the side" of students with disabilities, and showing them "that you understand." Nora also suggested that university faculty in departments of education should emphasize to pre-service teachers that "you [will] always have a student that may not be diagnosed but has some difficulties" and "prepare future teachers" to support all students.

Relatedly, participants provided recommendations for ways in which professionals can better support students with disabilities. Nora suggested that college professors "look at your students and say, 'Even if you don't have disabilities you can come talk to me if you need help. I will help. That's what I am here for. I will help you.'" She also stressed the "importance of professors reading the disability portion of the syllabus:"

> When professors go over the syllabus and come to the disabilities section and say, "You can read that..." or pass by it, it discredits those with disabilities. It sends a message that they are not important, the typical learners are more important…. It continues the stigma and view of those with disabilities that they are less than, ignored, or not a priority.

Other participants recommended that educators provide necessary and officially required academic accommodations while also facilitating peer-to-peer support and addressing depression "early on," before students find themselves in crisis.

Another form of professional support frequently recommended by participants was to share information and strategies with students and their families. Examples of information participants wished they would have known included how to "get resources" in school or at work, how to "advocate" for themselves, information about "government benefits," and how to become "more responsible and independent." Nora and Rûna also recommended that educational professionals in high school and college prepare students with disabilities for discrimination that they may experience in the workplace after graduation. Rûna stated:

> What do you do when you're being discriminated against?... So all of a sudden you're like well, can't change it I'm disabled. Can't change it that I have an asshole as a boss. So what do you do? These are preparations that at the high school and undergrad [levels] are not addressed.

These participants recommended that professionals "arm" students "to be comfortable enough to speak up for themselves" and "know the lived reality that you might be kicked" because "at the end of the day," places of employment do not adhere to the "fluffy diversity policy on the [company] website." Rûna and Nora both recommended high school educators and disability service office staff in college not only explain rights afforded under the Americans with Disabilities Act, but also what constitutes as a "reasonable accommodation" and advice on whether or not they should disclose their disabilities, and if so, how and when.

Family recommendations. Participants made basic recommendations for families of college students with disabilities, including destigmatizing disability within the family unit by talking about disabilities, setting high expectations, and openly discussing student needs, strengths, strategies, and resources. In general, participants wished their parents were more "hands-on" to help them locate available services and supports following high school. Delmy suggested that families visit college campuses with their students to "see what [colleges] offer for disability services so they can find the best way to help their child that's going into college." However, participants also recommended that "helicopter parents…who do everything for their kid" do their child a "disservice" by not teaching them to develop "responsibility" and "their own tool kit to survive" more independently into adulthood.

Student recommendations. Participants primarily recommended that college students with disabilities "always advocate" for themselves and "not be afraid" to ask for help in college because "nobody is going to do it for you." Participants suggested that other students "be themselves," "don't shy away from your disability," "be self-aware [if they are] feeling anxious or depressed," and "contact the disability office…to see what resources they provide." Participants also recommended that students learn "take care of yourself" without the support of their parents, as Shivani noted: "It hit me that I was alone. No one is calling my name. No one is serving me food. I had to control my own schedule- set rules for myself. It's a lot of self-management." Employing time management skills and self-discipline, such as "getting yourself in a position where your brain is ready to learn," or independently engaging in "med management" also emerged as a recommendation across several participants.

Participants also recommended that students with disabilities investigate "school values" "university culture," "disability services offered," and "social life" when deciding where to attend college to ensure that it aligns with their own preferences and needs. Similarly, participants suggested "looking at faculty member ratings," course sizes, and teaching assistant ratios to make informed decisions about the courses they take. Finally, participants recommended students "try to enjoy and have fun" in college and take advantage of college as "a very unique experience" to find a "support group" or "friends…to talk to."

Discussion

The purpose of this study is to explore the perceptions and experiences of college students with disabilities, including their preparation for college. Participants noted cycles of disempowerment and empowerment in which they focused on both positive and negative aspects of receiving a disability diagnosis, including experiencing self-doubt and confusion, as well as a diagnosis providing relief and serving as a way to legitimize their need for services and supports. This finding contributes to an understanding of both the positive and negative aspects of receiving a diagnosis can have on students and how professionals may support individuals to mitigate negative experiences and facilitate positive outcomes. Participants also reported that many educational professionals were either unsure or unwilling to provide appropriate accommodations and that professionals demonstrating warmth and genuine care for their wellbeing was as much, if not more important than academic accommodations. These findings are also consistent with literature that highlights a lack of preparation of university faculty and staff to effectively support students with disabilities with intensive academic, social, or mental health needs (Dipeolu et al., 2015; Dryer, Henning, Tyson, & Shaw, 2016; Hong, 2015; Odom & Wong, 2015) and the impact of educator dispositions (Francis, Blue-Banning, Turnbull, Haines, & Gross, 2016). However, these findings contribute to the literature by presenting the unique perspectives of adults with disabilities with varied educational experiences and providing recommendations for professionals to better support students (e.g., increase their knowledge of disabilities and individualized accommodations, teach students how to deal with discrimination and access available resources). Participants also noted that mental health support was an area in which individuals require greater support and professionals need better training; a need consistently noted in the literature on high school and college students with disabilities (Francis et al., 2018; Poppen, Sinclair, Hirano, Lindstrom, & Unruh, 2016). These issues and experiences caused participants to engage in a "constant fight" to experience success in college and resulted in a need for ongoing personal resilience and self-advocacy.

Participant inclusive education experiences also provided an interesting and much needed student perspective of the long-term influence of inclusion. Several participants, but primarily Rûna and Nora indicated that inclusive educational experiences resulted in a lack of belonging and support. In fact, all participants described feeling isolated and recommended that other students with disabilities locate other peers with disabilities for support. This finding is consistent with literature that cites a sense of isolation among students with disabilities (Dryer, et al., 2016; Van Hees et al., 2014), but, in some ways, contradicts literature that bolsters the benefits of inclusion, including expanded social circles, and feelings of belonging (Dessemontet, Bless, & Morin, 2012; Francis et al., 2016). Further, this study adds information on the outcomes of inclusion in high school, which is not often reported in the literature (Chesmore, Ou, & Reynolds, 2016).

Finally, although it was not central to our research questions, all participants discussed the influence of interactions with their families. This finding supports literature documenting the ongoing roles that families play in the lives of individuals with disabilities (Cullaty, 2011). However, this study adds information about the preferences of college students with disabilities, as well as the critical role that family culture plays in college student experiences. For example, although family culture and expectations resulted in feelings of isolation and insecurity for several participants, all participants also provided at least one unprompted example of a way in which a member of their family provided them support. It is clear that family interactions are highly influential for all individuals (Gilbert, 2004), but this study indicates that these experiences are likely more impactful for U.S. college students with disabilities from non-Western backgrounds than those from Western backgrounds.

Limitations

This study has four primary limitations. First, our initial recruitment procedures of distributing a survey through the university disability service office prevented us from directly contacting participants, thus diminishing our ability to control to whom the initial offer to participant was offered. Second, this study relied on convenience sampling to report the in-depth experiences of eight participants. Although qualitative research is not intended to be generalized across populations (Bogdan & Biklen, 2007), the sampling techniques used and relatively small sample size diminishes our ability to ensure that our themes reflect the experiences of the majority of students with disabilities registered with the disability service office. Third, aspects of participant characteristics varied widely (e.g., number of years in college, disability diagnosis) and reflect the diversity of the university they attended. For example, a recent report indicates that students attending the university come from over 130 countries and three of the eight participants were immigrants or from immigrant families. However, we are unable to gain access to disability service office records to determine whether the characteristics of the participants are representative of all students served by the office. Fourth, although there are benefits from collected qualitative data in-person (Opdenakker, 2006), the principal investigators conducted four interviews over the phone due to participant preferences.

Implications

This study highlights the need for pre-service and in-service professional development for K-12 educators and college faculty/staff on how to (a) better understand the nuances of different disabilities across individuals; (b) provide effective accommodations; (c) assist students to locate resources, services, and supports after graduation; (d) prepare students for barriers they may experience in college and the workplace; and (e) provide emotional support to students with disabilities. In addition, study findings indicate that college students continue to interact with and turn to their families for support, even though families do not always provide effective support for their loved ones with disabilities or promote their independence. Students stated that they wanted their families to maintain high expectations and support them in locating and accessing resources after high school, but that it was important from them to not to become “helicopter” parents so that students could independently find their way. These actions can be encouraged by secondary and higher education professionals providing families with parent workshops on how to engage in supported decision-making and connecting families to information and community resources (e.g., Center for Independent Living, vocational rehabilitation; Francis, Fuchs, Johnson, Gordon, & Grant, 2016). Shivani also recommended that universities provide two seminars during freshman orientation: one for the students and one for their families, with both focusing on independence while respecting cultural norms and differences. Further, high school and college professionals need to develop a stronger understanding of cultural differences related to family expectations and conceptualizations of disability in order to best support students from varying cultural backgrounds. This can be accomplished by providing person-centered planning processes for individual students (Haines, Francis, Shepherd, Ziegler, & Mabika, 2017), collaborating with cultural brokers, or by learning from guest speakers (e.g., student groups) with expertise in specific cultures.

Mental health also emerged as an ongoing need among participants. High schools and universities should consider conducting universal screening for all students to determine the nature and degree of their mental health needs. Participants recommended that educators consider social and emotional development as a primary focus when working with students with disabilities, and that mental health supports and services should be available to all students, regardless of diagnoses. Education settings may also consider offering students the opportunity to briefly consult with mental health experts such as school psychologists or social workers to determine if additional follow up support is necessary, offer basic coping and support strategies to meet student needs, and provide suggestions as to where students may locate additional support on and off campus. Similarly, participants indicated a need for supportive peer groups with other students with disabilities so they can find peers to whom they can relate, particularly during stressful times. High schools and universities can collaborate with student leaders to create face-to-face or online student organizations to reduce isolation, share strategies, and generally provide emotional, logistical, and social support (Francis et al., 2018).

Finally, although inclusive educational practices can result in numerous benefits (Chesmore et al., 2016; Dessemontet et al., 2012), our findings indicate that educators should maximize student outcomes by acknowledging disability as part of the natural human experience in order to increase an understanding and comfort among all stakeholders, decrease stigma, and help individuals with disabilities to access resources and systems of support (including other people with similar disabilities). Participants recommended that educators need more information about disabilities, including how to recognize various disabilities, make appropriate modifications, and use technology to support the independence of students. They also spoke of a need for information sharing with students and their families and for educators to better prepare students with disabilities for "real life." When speaking of the cycle of empowerment and disempowerment, participants stated that respect for all individuals was of the utmost importance in secondary and higher education settings. All students need to feel safe, validated, and that they treated fairly and with dignity.

Future Research

Future research should seek to recruit larger numbers of participants with greater levels of diversity. More specifically, researchers should seek to purposefully recruit non-majority race/culture and historically marginalized populations to provide important information on the influence of social capital, cultural values related to family interdependence, and other cultural values and norms (including conceptualizations of disability self-determination) that are crucial for facilitating positive outcomes for all stakeholders (Trainor, 2005, 2010). Replication of this study with specific student populations, such as students with Autism Spectrum Disorder who are increasingly attending college (Brown & DiGaldo, 2011), would provide important information for professionals to focus on the specific needs of each disability population.

Of the 23 students who originally volunteered to participate in this study, only eight completed an interview. Additional research is need to determine more effective ways to successfully recruit college students with disabilities to engage in this important line of research. Moreover, an examination of the perspectives of education professionals and families related to the key themes that emerged in this study would provide a deeper understanding of ways in which the field may improve student outcomes.

In addition, given the positive and negative discussions related to diagnosis and inclusion, more research is needed to determine the most effective methods for ensuring that receiving a diagnosis is an empowering rather than traumatic experience and that inclusion does not incidentally result in isolation and limited access to required information, resources, and support. Participants also spoke about the need for mental health services; future research is needed to develop a comprehensive framework and accompanying strategies to address mental health needs among diverse college-age students with disabilities.

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Table 1

Participant Demographic Information

Pseudonym	Primary Disability	Primary Support Need	Gender	Race/ Ethnicity	Language Used at Home	Age in Years	Years in College	Residence
Tae	Mental health	Self-management	Make	Asian/ Asian American	English	23	4	Off campus
Rodney	Multiple disabilities	Academics	Make	White/ Caucasian	English	25 or older	5 or more	Off campus
Shivani	Mental health	Vocational	Female	Asian/ Asian American	English	18	Less than 1	Off campus
Nora	Specific learning disability	Academics	Female	White/ Caucasian	English	25 or older	5 or more	Off campus
Rûna	Hearing impairment	Self-Advocacy	Female	Middle Eastern	Kurdish	24	4	Off campus
Lydia	Other health impairment	Vocational	Female	White/ Caucasian	English	25 or older	5 or more	Off campus
Landon	Visual impairment	Vocational	Male	White/ Caucasian	English	19	1	Off campus
Delmy	Hearing impairment/ Autism	Academic	Female	White/ Caucasian	English	24	5 or more	Off campus

Note. Self-management needs included support in organization, stress management, mental health, and time management. Academic needs included support in coursework, writing, and test-taking. Vocational needs included career awareness, workplace skills, and interviewing. Self-advocacy needs included requesting support and a knowledge of rights. Lydia’s other health impairment was attention deficit disorder (ADD).