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College Student Narratives About Learning and Using Self-advocacy Skills

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Abstract

Self-advocacy is the ability to communicate one's needs and wants and to make decisions about the supports needed to achieve them (Stodden, Conway, & Chang, 2003). Research shows self-advocacy skills are related to academic performance and successful adaptation to college (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray, Lombardi, & Kosty, 2014; Thoma & Wehmeyer, 2005). Yet, few studies have documented how youth learn to self-advocate and even fewer have delved deeply into how or when students use self-advocacy skills in college. Narratives gleaned from eight students with disabilities in a qualitative grounded theory study begin to fill this gap. Participants reported learning self-advocacy skills from family members and educators early in life. Findings from this study also demonstrate that college students utilized self-advocacy skills in three different ways: proactively, reactively, and retrospectively. Recommendations to enhance the self-advocacy skills of students with disabilities are provided for family members, K-12 personnel, and postsecondary educators.

Keywords: Self-advocacy, grounded theory, transition to college, self-determination

Students with disabilities are a growing population in postsecondary settings. Tracking a national sample of students who were identified as having a disability in high school, Newman et al. (2011) found that eight years after high school graduation, 60% of the students enrolled in some type of postsecondary institution. However, students with disabilities were substantially less likely to attend 4-year colleges and universities than youth from the general population (18.8% of students with disabilities compared to 40.2% for the general population). This number is even lower for particular sub-populations of students with disabilities, including students with intellectual disabilities, emotional disturbances, and those with multiple disabilities. According to the National Longitudinal Transition Study 2 (NLTS2) survey, students with visual impairments, those with hearing impairments, and those with speech/language impairments were among the most likely to enroll in 4-year colleges and universities. Mirroring trends for the general population, students with disabilities from families with incomes under $25,000 were less likely to enroll in a postsecondary institution than were students from families with incomes over $50,000. However, unlike trends in the general population, there were no differences by gender or race in the likelihood of enrolling in a postsecondary institution among students with disabilities (Newman et al., 2011).

Studies indicate adjustment to college for students with disabilities can be difficult, leading to higher rates of dropping out (Dowrick, Anderson, Heyer, & Acosta, 2005; Murray, Lombardi, & Kosty, 2014; Murray, Goldstein, Nourse, & Edgar, 2000). Many students who begin college do not graduate. The 2011 report from the NTLS2 study found that eight years after high school, fewer students with disabilities who began college graduated within this time frame (41%) in comparison to the general population (52%). For students attending 4-year colleges and universities, the rate of completion for students with disabilities was even lower, with 34% graduating within the eight year time frame (Newman et al., 2011).

Research with postsecondary students suggests that self-advocacy skills are related to adaptation to college, persistence, and academic performance (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray et al., 2014; Thoma & Wehmeyer, 2005). Self-advocacy is the ability to communicate one's needs and wants and to make decisions about the supports needed to achieve them (Stodden, Conway, & Chang, 2003). Yet, we know little about how students with disabilities learn self-advocacy skills. Moreover, we have no data about if, when, and how students utilize those skills during their first year of college. This paper begins to fill that gap by providing qualitative evidence regarding the development of self-advocacy skills from the perspective of eight first-year students with non-visible disabilities at a mid-sized public university in the Northeast. It should be noted that the nature of self-advocacy might be different for students with non-visible disabilities than for those with visible disabilities. First, the students have to make a conscious choice to self-advocate. Second, they have to disclose their disability and accommodation needs because their disability is not apparent to the receiver.

Analysis of student narratives from a grounded theory study yielded rich descriptions about self-advocacy from college students with disabilities. In this paper we explicate how self-advocacy was an on-going and adaptive process for young people with disabilities. Students in our study learned self-advocacy skills early in life from parents and educators and honed their skills as they engaged in proactive, reactive, and retrospective self-advocacy in college. In accordance with qualitative tenets requiring thick, rich description of a particular phenomenon, this paper offers details about the under-studied phenomenon of self-advocacy by college students.

Literature Review

In this review, we focus on students with non-visible disabilities, learning disabilities, psychiatric disabilities, and general disabilities in order to illustrate how self-advocacy is conceptualized across a range of disabilities. This literature comes from a variety of disciplines including education, psychology, social work, and vocational rehabilitation. Our choice to concentrate on self-advocacy in the literature review stemmed from multiple participants in our study who specifically used the term "self-advocacy" during their interviews. In the following sections, we highlight the educational context for college students with disabilities and then delve into the literature about self-advocacy.

Disclosure and Accommodations

As students make the transition from the structured and guided educational process of high school to a self-directed path after graduation, the importance of self-advocacy increases. According to the stipulations of the Individuals with Disabilities Education Act ([IDEA]; 1997) elementary and secondary schools are responsible for identification, assessment, and development of educational plans for students with disabilities. Once a person with a disability moves to postsecondary education the process of receiving accommodations significantly changes because they must self-identify, undergo assessment, and seek services. This shift of responsibility from the school to the student requires college students to utilize self-advocacy skills (Stodden et al., 2003). However, many college students do not engage in even the most fundamental forms of self-advocacy such as disclosure, requesting accommodations, or seeking special services. In the NTLS2 study only 28% of students reported that they self-identified and informed their postsecondary institution of their disability. Although 87% of the sample had received accommodations in high school, only 19% reported receiving accommodations at their postsecondary institution (Newman et al., 2011).

In the IDEIA 2004 amendment, specific revisions were made to address the transition from secondary to postsecondary life for youth with disabilities. It states that beginning in the sixteenth year, transition should be "a coordinated set of activities based on students' strengths, preferences, and interests," and requires students be included in transition planning activities (§300.43[a] [1-2]). It is considered a violation of IDEA/IDEIA if students have not been provided with supports; to identify their strengths and areas of need; to set goals and make plans to achieve them; and to know their rights, if any, under Part B as they move out of secondary education. It is unclear from the dated literature if this is happening for contemporary college students with disabilities (Janiga & Costenbader, 2002; Trainor, 2005).

Research shows that many young people choose not to disclose their disability or request accommodations through the office of disabilities upon entering college (Belch, 2011; Hadley, 2006; Megivern, Pellerito, & Mowbray, 2003; Vickerman & Blundell, 2010; Wagner, Newman, Cameto, Garza, & Levine, 2005). Yet, disclosing one's disability to university personnel is a key step in requesting accommodations (Olkin, 1999; Salzer, Wick, & Rogers, 2008). Studies suggest that students have a variety of reasons for not disclosing their disability and requesting accommodations including embarrassment about disclosing one's disability to faculty and fear of stigmatization from peers or faculty. However, the most common reason given by students who did not ask for accommodations was that they did not need them (Newman et al., 2011; Olkin, 1999; Salzer et al., 2008).

Self-Advocacy

In some literature, self-advocacy is incorporated as a component of the larger construct of self-determination, which is a combination of skills, knowledge, and beliefs that enable a person to engage in goal directed self-regulated behavior (Abery & Stanclifee, 2003; Anctil, Ishikawa, & Scott, 2008; Test, Fowler, Wood, Brewer, & Eddy, 2005; Thoma & Wehmeyer, 2005). Self-determination is associated with important educational processes and outcomes such as academic success, and persistence (Getzel, & Thoma, 2008). Research has described the developmental process and predictors of self-determination from early childhood to early adulthood, but little emphasis has been placed on the adaptive process of self-advocacy and what happens when students enroll in college (Heller et al., 2011; Shogren et al., 2007).

In this literature review, we focus on self-advocacy independently of self-determination. Our rationale for this emphasis is rooted in our qualitative methodological perspective. Since a hallmark of qualitative research is honoring an emic (i.e., participant) perspective (Jones, Torres, & Arminio, 2013), we have used the term "self-advocacy" to reflect student perspectives. Moreover, our participants consistently utilized this term in a way that aligned with the narrow concept of self-advocacy versus the larger construct of self-determination.

While educators might use slightly different definitions of self-advocacy in practice, we have selected a definition cited frequently in the scholarly literature. Stodden et al. (2003) described self-advocacy as the ability to communicate one's needs and wants and to make decisions about the supports needed to achieve them. Key components of self-advocacy are knowledge of self, knowledge of rights, ability to communicate, and ability to be a leader. Knowledge of self refers to understanding one's preferences, goals, learning style, strengths, weaknesses, accommodation needs and the characteristics of one's disability. Knowledge of rights refers to understanding personal rights, community rights, educational rights, steps to correct violations, and steps to advocate for change (Test et al., 2005). Self-advocacy skills draw heavily on the cognitive processes called executive functions. The executive function skills are planning and organizing actions. They include working memory, verbal self-regulation, inhibition of behavior, and motor control (Wicks-Nelson & Israel, 2013). Deficits in executive functioning may interfere with the effective use of available resources in the college setting (Wolf, 2001).

Self-advocacy skills are related to adaptation to, and persistence in college, as well as academic performance (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray, et al. 2014; Thoma & Wehmeyer, 2005). Results from two recent studies show that students with higher levels of self-reported self-advocacy skills also reported higher levels of adaptation to college (Adams & Proctor, 2010; Murray et al., 2014). Specific self-advocacy skills shown to promote students' success in higher education include: utilizing tutoring labs and disability services, forming relationships with instructors, and having a support system on campus (Adams & Proctor, 2010; Getzel & Thoma, 2008).

Influences on Self-Advocacy

Although the evidence suggests that self-advocacy is related to important educational success measures such as adaptation, persistence, and academic performance (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray et al., 2014; Thoma & Wehmeyer, 2005), we know little about how self-advocacy skills are developed. In the period of late adolescence, young people can be expected to contribute more actively to their own development by setting goals and using effective strategies to achieve those goals (Bandura, 2006; Larson, 2011). Three small, but important bodies of literature suggest that young people learn self-advocacy skills from families, educators, and peers.

Families. Learning to advocate for one's self can begin in childhood and researchers have found that family support is associated with the development of self-advocacy (Dowrick et al., 2005; Murray et al., 2014; Murray & Naranjo, 2008). Family members can encourage students to be successful, but they can also undermine self-advocacy by being overprotective and communicating worry or doubt about their child's ability to succeed (Dowrick et al., 2005; Janiga & Costenbader, 2002). Murray and Naranjo (2008) found that successful high school students indicated that family support and being held accountable were crucial to their persistence in school. Students also discussed observing their parents advocate on their behalf. Researchers found that college students who categorized themselves as highly adjusted also had higher scores on self-reported measures of self-advocacy and family support (Murray et al., 2014).

Educators. The transition planning process from high school to adulthood is an important part of the special education process. It is a natural time for students with disabilities to engage in self-advocacy behaviors. Murray and Naranjo (2008) described the experiences of 11 students with disabilities who graduated from a high-risk urban high school. The students said that, because they were willing to seek support from teachers and were persistent, sometimes going in after school, they eventually got the help that was necessary. Unfortunately, high school students do not always have this opportunity (Janiga & Costenbader, 2002; Trainor, 2005). In one study, college service coordinators from 74 colleges indicated that students were not prepared to self-advocate (Janiga & Costenbader, 2002). This was seen as the greatest weakness of transition planning at the time. Similarly, findings from a qualitative study indicated that many students did not practice self-advocacy in school (Trainor, 2005).

Peers. Very few studies have addressed the influence of peers on the development of self-advocacy and self-determination. In a study of high school students with disabilities in high-risk urban areas, Murray and Naranjo (2008) suggested that social isolation was a protective factor in graduating from high school because students were not interacting with deviant peers. College students with ADHD reported receiving more support from their family in contrast to a comparison group of college students without this diagnosis who reported that they received more support from their peers (Wilmshurst, Peele, & Wilmhurst, 2011). Using a focus group design, Dowrick et al. (2005) found that college students with disabilities learned self-advocacy skills from discussions with and observations of college-aged peers without disabilities. They also indicated that peers with disabilities provided them with information about services, supports, and advocacy (Dowrick et al., 2005).

Methodology

Grounded theory methods were utilized in this study. Grounded theory emphasizes theory building through a complex and emergent process versus research designs that use a priori assumptions and hypothesis testing (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). Since grounded theory is designed for generating theories of process, change, or sequence (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998) it was ideal for the larger project from which these self-advocacy data were gleaned.

The purpose of the larger study was to develop a grounded theory about the development of a sense of belonging for diverse, first-year college students. The overarching research question for that study was: How do first-year students define and describe the development of a sense of belonging? The main study findings, including a theoretical model of belonging, are presented elsewhere (Vaccaro, Daly-Cano, & Newman, in press). This paper provides an in-depth analysis of *one* key aspect of our theoretical model that emerged from a subset of college students with disabilities – self-advocacy. This paper is not about belonging; it is an in-depth exploration of the key emergent study theme of self-advocacy. Qualitative designs in general, and grounded theory methods in particular, emphasize the importance of honoring emergent concepts even if they seem to relate only tangentially to an initial research question. Moreover, Strauss and Corbin (1990) argue that important properties can emerge in addition to, or distinct from, a larger theory. In this project, we found that self-advocacy was not only an integral part of belonging (Vacarro et al., in press), but also an emergent topic worthy of in-depth analysis in its own right. Given that prior research has documented the importance of self-advocacy for educational success, we decided to share this sub-set of our research findings about college students learning and utilizing self-advocacy skills.

Students in the study were recruited from a public research university with 13,000 students, of which 3,000 were first-year students. Recruitment took place in introductory and general education courses, first-year residence halls, and diversity centers on campus (e.g., LGBTQ center, women's center, disability services office, and Hillel). Our total sample was comprised of 51 first year students. This paper offers an analysis of the experiences of the eight participants who self-identified as students with disabilities. Through our constant comparative (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998) analytic method, we determined this subset of students had a story to tell about self-advocacy that differed from the rest of our study participants for whom the concept of self-advocacy did not emerge as salient.

The students with disabilities were diverse in age (18-32 years old), major, and disability. Students self-reported their disabilities as Asperger's, bipolar disorder, obsessive compulsive disorder, retinopathy of prematurity, irritable bowel disease, and three had learning disabilities. Participants were given the opportunity to offer details about their disabilities on a demographic form and during interviews. Two students with learning disabilities shared more specific diagnoses. One had dyslexia and another described her learning disability as "memory and audio." The third student chose not to offer any detail beyond "learning disability" and we respected that level of disclosure.

Participants were not very diverse in terms of race, ethnicity, or gender. Six students were white and two were students of color, one Latino and the other African American. Two men and six women with disabilities participated in the study. Information about socioeconomic status was not collected.

Data Collection and Analysis

Semi-structured, individual interviews served as the primary mode of data collection for this study. Students were provided detailed study information and invited to a series of two individual interviews, one in the fall semester and one in the spring. Eight students with disabilities participated in the fall and seven returned for a spring interview. In the first round of interviews, we asked broad questions such as:

- What is it like to be a student at X College?
- Can you talk about anything that happened before college that helped you to adjust?
- Were there any experiences or people who were especially important in influencing your transition and sense of belonging, either positively or negatively?

The spring protocol was slightly more focused. We used emergent themes from the first round of interviews to shape the questions. To more deeply explore the emergent theme of self-advocacy, we asked:

- If you could go back in time, what would you do differently/ similarly?
- What would you tell another student with X disability about coming to this university?

In line with the grounded theory principle of constant comparative analysis (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998), the research team engaged in a back and forth movement between data collection and analysis throughout the research process. The team met every other week to discuss themes that emerged during the interviews. Each member of the research team kept memos about the research process. Memos are a "researcher's record of analysis, thoughts, interpretations, questions, and directions for further data collection" (Strauss & Corbin, 1990, p. 110). Memos guided research team discussions and served as a method of triangulation for the codes gleaned from the interview transcripts.

The interview transcripts were analyzed using open, axial, and selective coding (Strauss & Corbin, 1990, 1998). Researchers first read the transcripts in their entirety noting key topics in the form of potential open codes. Only topics that yielded 100% agreement among the research team were retained. Once the list of open codes was decided upon, we used axial coding to connect categories into broad themes under which all open codes were subsumed. This process of data analysis was repeated for the second round of interviews. Once open and axial codes were complete for both the fall and spring interviews, we engaged in selective coding to connect key categories and build a story about the self-advocacy experiences of students with disabilities. That process involved "selecting the core category, systematically relating it to other categories, validating those relationships [through discrepant case analysis and confirming examples], and filling in categories that need further refinement and development" (Strauss & Corbin, 1990, p. 116). The current paper offers an in-depth presentation of findings related to the category of self-advocacy yielded from axial coding. Participant narratives illustrate what students had to say about experiences prior to college that prepared them to self-advocate and their experiences of self-advocacy during the first year of college.

Several techniques were implemented to ensure trustworthiness of the study findings (Jones et al., 2013). First, for purposes of corroboration, data from the initial interviews were triangulated with data from the second interviews. The research team also engaged in analytic triangulation (Patton, 2002) whereby we coded each transcript independently and then revised the codes as a group. Once the axial coding frame for each round of interviews was solidified, two members of the research team re-read the transcripts and assigned axial codes. We only retained coded quotes that yielded 100% agreement from the researchers.

We utilized negative case analysis (Glesne, 1999; Jones et al., 2013) when a participant's experiences ran counter to our emergent codes. Emergent themes from the interviews were also used for member checking. After interview two, students were invited to offer feedback on both the themes and research process. At biweekly meetings the team engaged in reflective discussions about our assumptions, concerns, and questions related to the experiences of college students with disabilities (Glesne, 1999; Jones et al., 2013) and how our own social identities and experiences shaped our analyses. The research team consisted of two full time faculty members, two Doctoral students, two Masters level students, and an undergraduate. Team members were women from a range of ages, ethnicities, and sexual orientations.

Findings

The following findings are organized in three sections. First, we offer evidence to show that participants understood the importance of self-advocacy in college. Second, we explicate how and from whom students learned self-advocacy skills. All of our participants learned self-advocacy prior to entering college through both intentional teachings and more subtle support messages from family and educators. Our final section describes how students engaged in self-advocacy in three distinct ways during the first year of college: proactively, reactively, and retrospectively.

The Importance of Self-Advocacy

During interviews, students were asked a variety of questions about their transition to the university and through their first year. In response to the questions about people or processes that assisted with their transition and advice they would offer to other students with disabilities, the concept of self-advocacy emerged regularly. The ability to self-advocate means students have the capacity to communicate needs and to make decisions about the support they need to achieve their goals (Stodden et al., 2003).

Key components of self-advocacy include knowledge of self (e.g., one's disability, strengths, weaknesses) and one's rights (Test et al., 2005). Students gave detailed examples of how they understood their disability and how they thought it was going to impact their lives on a university campus. Barry, a student with Obsessive Compulsive Disorder, described his apprehension about having a college roommate. He said:

> It's just nerve-wracking to be coming to school. I'm a fairly neat person, and it's difficult enough. If I end up living with someone who's a slob, it would freak me out. It's just something that I have to take care of . . . But I have everything figured out so I can take care of myself.

Barry's comment about "having everything figured out" and his confidence in his ability to "take care of myself" allude to confidence in his self-advocacy skills. Later in the interview, he explained how his self-advocacy skills served him well in college when he said, "I am able to step up and get what I need in order to do well."

Naomi described the difficulty of having Irritable Bowel Disease (IBD) and being around people who do not know about it. She said:

> I have IBD. I do have to run to the bathroom a lot. It can't be helped, [it's] just part of it. Having to run down the hallway … it's not noticeable really. Except my friend knows, which is good, because when I have to walk out of the conversation or something she knows . . . Otherwise it's kind of awkward around new people who don't know.

Her comment that "it can't be helped" shows that she understands her disability and she has developed strategies to deal with the awkwardness of leaving conversations abruptly. Self-awareness and coping strategies are both components of self-advocacy.

Jennifer described her understanding of herself and how she interacts with others. The following short quote chronicles her journey from self-dislike to an understanding and acceptance of her disability.

> It took a long time to like myself because … I didn't understand why I was different. I didn't understand why I didn't get it the way they got it. And until I could make those connections whether it was in work or whatever. Liking myself … made me comfortable enough to make connections with other people . . . like any time you have a learning disability you have to work harder . . . and you almost have to change what people think. Just because I have a learning disability doesn't mean I am not intelligent. It just means I don't think like you think. My connections are different.

This self-advocacy quote shows how understanding the nature of her disability (including her strengths and weaknesses) contributed to her self-acceptance and led to more effective social connections. It also highlights how she developed self-advocacy strategies to respond to others who made deficit assumptions based upon her learning disability.

Learning to Self-Advocate

Most students described how they learned to self-advocate from family members and educators in K-12 settings. Data from this study suggest there were three different contexts in which students learned self-advocacy from family and educators. First, students gave examples of general messages of support. Second, they gave examples of instances when they were intentionally taught to self-advocate in familial and K-12 school settings. Third, students were provided specific instructions to help them self-advocate in college.

Families. Parents encouraged their children to learn and utilize self-advocacy skills via both direct teachings and indirect messaging. Students talked about receiving general messages from family members about the challenges ahead in life. In the context of those life challenges, family members also conveyed general messages of support such as: "We support you" and "We want you to know that you can succeed." These informal and inspirational communications often served as the impetus for students to learn self-advocacy skills since they knew they would need them. Emily, a student with a learning disability, explained how her parents and family taught her to take advantage of different life opportunities. They shared their personal struggles with her so that she would learn life was full of hurdles that she would need to overcome. They also encouraged her to utilize a key self-advocacy strategy, asking for help when she needed it. She said:

> I think my parents always told me that there is a lot to offer. You know? Like, there's so many different things out there … and so many people that you can meet. So if you need help with [anything], or within my major, if I see other people, I can ask them [for help]. High school is different . . . because [in college] everything depends on you now.

Emily's quote suggests that she understood that in college she was required to self-advocate when she explained "everything depends on you now."

Lisa, a student with bipolar disorder, received unconditional support from her family, which allowed her a sense of security when she attempted to self-advocate and be independent. She learned that she needed to advocate for herself, but she was never alone. She had the love and support of her family as a safety net if needed. She said:

> My family is always there for me. So I know that if I need help I can always go to them and go home if I need to. So they're helpful when it comes to transitioning of course. And my sister is always there so I can talk to her. And so if I ever have problems you know I have someone there. You know that's good [for] transitioning.

While some students explained how general encouragement helped them learn to self-advocate, others were intentionally taught the importance of, and need for, self-advocacy. Often these lessons came in the form of tough love, whereby families required youth to learn to self-advocate by fending for themselves. Jessica talked about how her parents taught her to self-advocate by putting her in situations where they were not available to help. For instance, they intentionally placed Jessica in unfamiliar settings (i.e., summer camp) so she would be forced to self-advocate.

> My parents kind of started me off [learning self-advocacy skills] young . . . I was the biggest mama's girl. I would get like physically sick if I was away from my mom. I wouldn't do sleepovers or anything. And, they made me go to summer camp . . . in California and in Maine for one to two weeks … from third grade up. That's how I got started. So for a 13-year-old to go out of state for two weeks, is [a challenge]. But if I didn't do that, and didn't get comfortable doing that, I wouldn't have been an exchange student. If I wasn't an exchange student, I probably couldn't have gone so far [away] for college. You know? And I wouldn't have been as comfortable [at college]. So, it was like a chain reaction. My parents had a plan; they wanted me to, like, branch out. They did a good job. It worked.

Jessica understood that, while the process of learning to self-advocate was a challenge, it was an essential part of her journey toward being an independent adult. As she succeeded in each new setting, she gained the confidence to self-advocate anywhere, including college.

Finally, some young people were given deliberate preparation for collegiate level self-advocacy. Jessica and Ethan described how their parents told them to make contact with the disability services office before school started. Jessica shared, "I think my dad was like, 'Yeah, …look up disabilities.' I said, 'Okay, Dad.'" Similarly, Ethan explained, "I got an email from the disability service. And my parents really encouraged me to join it so I did."

Educators. Early in life, some of our participants had the good fortune of learning self-advocacy skills from teachers, aides, and other K-12 personnel. These early experiences were often challenging, but they helped students practice essential self-advocacy skills. Melissa, a student with a visual impairment, reflected upon her early memories of a kindergarten aide who was among the most influential people in her self-advocacy journey. She said:

> I got assigned an aide in kindergarten. One of the first things she taught me was that, if you can't see something, you gotta go tell the teacher. So I'd be sitting there and I would say, "I can't see the [board]." And she would be say, "I am not gonna go do it. You can't see it." So she would just sit and if I didn't go do something it just stayed the way it was. So she made me go up and ask for whatever I needed. I think it was probably one of the best things they ever did … even though I was in kindergarten and I didn't like it. I was like, "You're such meanies; you're making me do everything." It actually really paid off in the later years.

While Melissa referred to the aide and other educators as "meanies," she now understood how valuable early self-advocacy training was to her ability to be independent and self-advocate in college.

Educators also provided students with specific self-advocacy training for college. Melissa described how her high school advisor encouraged her to be responsible for describing her visual impairment and requesting accommodations in high school, even though her advisor or parents could have taken care of it. Melissa's advisor wanted her to practice self-advocacy before she arrived at college. She said:

> My advisor would say, "You need to write a letter to your teachers explaining what your visual impairment is, how you see, what your accommodations are." So I had to write the letter to the teachers. The teachers would still have to come to the Individual Education Program (IEP) meetings, but I was responsible for telling them on my own in a letter. And I think that was a really smart strategy because, when I came here [to college], I was able to call the student services office and say, "Okay, I need student services. What do I need as far as paperwork?"

Practicing these skills in high school made Melissa feel comfortable advocating in college by and for herself.

Self-Advocacy in College: Proactive, Reactive and Retrospective

The prior sections showed that our participants understood the need for self-advocacy and from whom they learned self-advocacy skills. Once students arrived at college, they approached self-advocacy in three different ways: proactively, reactively, and retrospectively.

Proactive. Students who engaged in proactive self-advocacy sought accommodations before needing them, typically before the semester began. Jessica discussed the importance of self-advocating but also the anxiety of doing it for the first time. She said:

> Before I had my parents to help me with meetings … and this time I was all on my own … I had to . . . self-advocate, you know? But that's obviously a skill you need for life and that's a skill you learn in college. So, I was happy I was doing that. But, that was just overwhelming because I [had] to go in to talk to my teachers and make that first move.

Melissa, a marine biology major with a visual impairment, explained that she emailed professors before the start of the fall semester and then spoke with them in person to explain her accommodations. She shared:

> I did it right after the semester started, but I emailed them in advance to let them know I was going to be in their class. And then, once I figured out when their office hours were, I set up an appointment. And, I still see them on a regular basis anyway just because it's good to check in.

Another student with a learning disability, Emily, described her proactive efforts to self-advocate, which included taking the initiative to "know [her] surroundings" and utilize the disability services office.

Ethan, a student with Asperger's, described going to see a therapist in the summer before beginning college. He understood his disability and knew he would struggle socially in the new setting. Therefore, Ethan proactively scheduled appointments with a therapist to prepare himself emotionally for the transition. He said, "One thing that made me [uncomfortable] was the transition. I had been getting some therapy to figure some things out because I was kind of having some mental issues." Jennifer discussed the importance of proactively looking for resources. She said, "I think [that it is] just really seeking stuff out. I'm a big resource person."

Lisa talked about taking classes at her current college as a non-matriculating student to make sure she felt comfortable before officially enrolling. She said, "I took a class over the summer here. I took Physics 1 and Physics 2 just to get the ball rolling. That was great. I was a non-matriculating student last semester, so that got my feet wet with getting into [this] college."

Emily talked about the importance of proactively getting to know the staff in the disability office so she had someone to talk to if she had a problem. She would advise other students with disabilities to be proactive in building relationships with the disability office staff. Emily stated:

> It's good to find your sources to know . . . your surroundings and where everything is. Try not to be shy, just talk, be outspoken so you can learn and know more things about this campus and the disability office . . . The more that you talk to them [the more] you will feel comfortable and you can go to them with any questions. They help you out a lot!

Narratives from Melissa, Emily, Ethan, Lisa and Jennifer suggest that, because they were socialized to understand the importance of self-advocacy earlier in life, they proactively self-advocated in college. However, being proactive was not the only way students self-advocated.

Reactive. In some cases, students had to step up and self-advocate in the face of a particular challenge or hurdle. We describe these students as reactively self-advocating. The following examples illustrate the ongoing adaptation required for effective self-advocacy. Even though all the students had prior experiences with self-advocacy, and many took steps to anticipate their needs, there were still emerging situations that required them to react.

Jennifer, a student with a learning disability, discussed negotiating with a professor about her test-taking accommodations. This discussion occurred because the faculty member was not offering her the accommodation she was due. She explained:

> I was like, "No, you said I could take my test, I get double the time." And then he said to me, "Okay, the quiz should take 20 minutes so you can have 30 minutes." "No, no, no I get 40 minutes . . ." And he's like, "Alright, well you can do it during the beginning of lab." Then I said, "No, I'm not doing it during the beginning of lab. That cuts into my time to do the lab."

Emily also gave an example of negotiating with a professor. While she had provided him with the appropriate documentation, the faculty member did not offer her the accommodations she needed. She said:

> One of my professors that I gave my papers to, he signed it but then didn't let me go in another room to take my test because he thought I was going to cheat or something. I said the teaching assistant (TA) could come with, I didn't really mind. I went to the disability office and talked to them and they contacted him and let him know. So then I had a separate room for my test.

Even though Emily and Jennifer both explained (in the previous section) how they proactively self-advocated, these quotes showed that there were instances where they also had to "react" to a situation where they were not receiving the support they needed.

Two other examples illustrate how students invented strategies to help them address emerging needs. Melissa described a solution to a visual problem in her chemistry lab:

> I have trouble reading the graduated cylinder, like the volume, so what we've done is I have a person who always comes over and I will say, "Well I think it says 6.25 milliliters," and they'll say, "that's close but it actually says 6.5 milliliters." So I have somebody double-check my measurements just because, with a visual impairment, it is hard to read through a glass graduated cylinder.

Jennifer, who has a learning disability, explained that in a nutrition class her instructor gave her the power-point slides in advance, but that was not quite working. So, she took notes on her copies of the power-point slides then she also obtained notes from the teaching assistant. After class, she compared both sets of notes. She explained how her strategy was "working out well because I'm able to see what I'm missing during the lecture."

A negative case analysis (Glesne, 1999; Jones et al., 2013) illustrated a situation where a student needed to reactively self-advocate, but did not do so. Lisa, a student with bipolar disorder, was enrolled in a health psychology course. The course included a required research assignment involving participation in a health-related intervention. Lisa complained that she felt coerced into participating in an assignment that would require a level of disclosure she was uncomfortable with. She said:

> One of the things that we got graded on was . . . being guinea pigs in their research… and that was just so frustrating … I was just one of – another person on their, like, check-off list that they forced me to do, so I didn't like that.

Lisa disclosed that the research (and corresponding assignment) was related to readiness to engage in behavioral change. To complete the class project, students were expected to disclose, and subsequently address, personal information that Lisa found intrusive and possibly emotionally distressing. This example illustrated a challenge where the requirements of a course touched a sensitive issue associated with the student's disability. While she alluded to the fact that she could (or should) have addressed the situation, ultimately, Lisa did not manage to modify the situation to her satisfaction. This example illustrates a case where a student recognized a need to reactively self-advocate, but did not act accordingly.

Retrospective. In this section we describe a third way that students self-advocated: retrospectively. Some students self-advocated only after they had not "done it well." In essence, these students learned from their mistakes and advocated for themselves after reflecting about their failures. Jessica, a nutrition student with dyslexia, talked about learning that she had to get her books put on CD before the start of the semester. She described learning from her mistakes as follows:

> Something I did wrong is I didn't tell them about books because I paid like $400 for books and I only used one of them, you know? I needed CDs for them and I didn't realize that I needed to ask for them ahead. I thought they had them and they didn't, so I didn't get them for, like, a month. That was my fault because I didn't plan out far enough ahead of time . . . You learn from things.

Melissa, a student with a visual impairment, explained her decision to modify her course load after learning that a schedule of five classes was too hard on her eyes. She said:

> I have visited my disabilities counselor a couple of times to set up classes for the next term to make sure my classes are not too visually taxing. I am doing the five-year plan instead of the four-year, because I discovered this semester trying to do five classes was too much.

Naomi, a student with irritable bowel disease, became very ill at the end of the first semester. She had a severe attack of ulcerative colitis, which resulted in her having to go home often. When asked what she thought caused the serious attack, Naomi realized that several issues were involved. She said, "Sometimes I can't handle the food in the cafeteria … that and probably just regular school work stress." So now, at the beginning of the new semester, she was feeling much better. She said, "Yeah, I have everything under control. I figured some things out, brought some food from home." In this case, Naomi had to reflect on the demands and resources of the campus that had an impact on her health and make some modifications that would allow her to manage her condition.

Finally, another student explained how she retrospectively learned to self-advocate in high school. This experience, in turn, promoted her self-advocacy in college. She explained:

> My senior year in high school I was taking trigonometry and I was not very good at it. It took me a while to build up the courage to go to the math-tutoring center down the hall and ask for help. But once I did, that also helped me to prepare for college because here on campus they have tutoring included in your tuition. Oh my gosh! I don't know what I would do without it.

It took some failures in trigonometry for this student to get the "courage" to self-advocate and utilize tutoring. In that setting, she retrospectively self-advocated, but the experience served as valuable part of her journey toward more proactive self-advocacy in college.

Discussion and Recommendations

Once in college, students with disabilities have to adjust to being more independent, adapt to a new environment, and make friends just like every other student. However, they also have the additional responsibility of contacting the disability services office, disclosing their disability, requesting accommodations, demonstrating a need for services, obtaining letters specifying their needed accommodations and then presenting those letters to professors. This is a complicated and time-consuming process, which may explain why so many students who received accommodations in secondary school fail to request them in college (Adams & Proctor, 2010; Anctil et al., 2008; Cawthon, & Cole, 2010; Dong & Lucas, 2013; Salzer et al., 2008). In this section, we synthesize our findings regarding the learning and implementation of self-advocacy skills described by college students with disabilities. In addition to drawing general conclusions from our study, we also offer five specific recommendations for families and schools.

Data from our interviews suggest that students with different disabilities come to the university with different needs, as well as varying amounts of prior experience and competence self-advocating. Effectively self-advocating requires knowledge of self and having strategies for information gathering, networking .and getting the system to acknowledge and respond to one's needs (Stodden et al., 2003; Test et al., 2005). Many of the students that we interviewed talked about how their parents or K-12 educators got them thinking about and practicing self-advocacy skills from a young age. They gave examples of how they learned and honed self-advocacy skills in different contexts at different points in their life: school, summer camp, study abroad programs, and work. They discussed how these experiences were opportunities to practice advocating on their own, but always with the support of educators and family.

In learning a skill such as self-advocacy, it is important to acknowledge that many students will not use this skill without deliberate and repeated instruction. While there is no prior literature about repeated instruction of self-advocacy skills per se, other literature points to the importance of intentionality in the learning process. For instance, studies of interventions for executive function development have demonstrated improvements among 4-12 year olds when deliberately taught those skills (Diamond & Lee 2011). In addition to deliberate and repeated instruction, our data suggest that young people also need multiple opportunities to practice in school, home, and community settings with the support of teachers and family. If students wait to practice self-advocacy until they enter college, it may be too late.

Our findings call attention to the importance of families and educators teaching self-advocacy skills and requiring students to practice these skills throughout their education. While youth may resist these efforts (e.g., feel like adults are being "meanies"), the long-term benefits of self-advocacy skill development are paramount. While this conclusion might seem obvious, it is necessary given the research that shows many students with disabilities come to college unprepared to self-advocate because of past reliance on parents, special education teachers, and a secondary school system that did not require self-advocacy (Janiga & Costenbader, 2002).

Recommendation One

Elementary and secondary schools should consider offering self-advocacy workshops where parents and children learn the importance of self-advocacy skills. Workshops could incorporate role playing to develop skills in assertiveness. Our data on reactive self-advocacy suggest that students will encounter situations where they have to push back against authority figures who do not provide required accommodations.

Many parents may not understand the long-term benefits of teaching children to be self-aware and advocate for themselves in IEP meetings and in everyday school settings. Teaching these skills may be especially important for youth with non-visible disabilities. Self-advocacy workshops can help families understand how and when it is appropriate to encourage youth to self-advocate and how to help a child move toward independence. While participants in our study had the benefit of early socialization about the importance of self-advocacy, not all youth receive this type of education.

Recommendation Two

The IEP meeting can be a logical place for students to practice self-advocacy skills. In fact, the IDEIA 2004 amendment stipulates that transition be "a coordinated set of activities based on students' strengths, preferences, and interests," and requires that students should be included in transition planning activities (§300.43[a][1-2]). It is considered a violation of IDEA/IDEIA if students have not been taught self-advocacy skills by the time they graduate from high school.

Barnard-Brak, Lecthenberger, and Lan (2010) found that students who participated in IEP meetings had higher levels of academic achievement in comparison to students who did not participate. However, student participation in an IEP meeting is not a guarantee of self-advocacy training. Even though students attended IEP meetings they did not always participate in meaningful ways (Trainor, 2008). Furthermore, a study of transition planning found that goals for self-advocacy were not included in the IEP of the majority of secondary students (Powers et al., 2005).

The IEP is one meeting a year and parents may feel responsible to advocate for their child during this meeting. While many parents feel it is their role to advocate, research shows that being overly protective or advocating on behalf of a child can undermine self-advocacy (Janiga & Costenbader, 2002).

Recommendation Three

In addition to encouraging students to practice specific self-advocacy skills, we recommend that family members also provide regular messages of support and affirmation. Participants in our study explained how generalized messages of support (e.g., "we support you") let them know they were not alone as they "tried out" self-advocacy skills. They were confident as they practiced self-advocacy efforts because they knew that they had a familial safety net if things went awry. Our qualitative evidence is similar to the findings by Wilmshurst et al. (2011) showing college students with ADHD rated parental emotional support higher than peer support in relation to resilience and well-being in college.

Recommendation Four

Parents and secondary school teachers and counselors must prepare students for the reality of postsecondary education where they are wholly responsible for self-advocacy (Stodden et al., 2003). Moreover, educators in both secondary and postsecondary settings should constantly remind students that, while being proactive is essential, there will be times when they have to be reactive or retrospective and learn from their failures. Our study indicated that students engaged in different types of strategies in the process of self-advocating. At times they were proactive and anticipated needing to ask for accommodations. Other times, students used their self-advocacy skills reactively in a moment when they had to negotiate to receive accommodations they were due. Finally, students utilized retrospective self-advocacy after experiencing lack of success at a collegiate task. Our findings suggest that, despite early self-advocacy socialization, college students still had a learning curve when they entered college.

Recommendation Five

In college, disability service providers and academic advisors should regularly have conversations with students about their efforts at self-advocacy. In those meetings, postsecondary educators can help students to assess the success of self-advocacy strategies and determine if modifications or other strategies would be more useful. In addition to these individualized conversations with students, postsecondary institutions should offer programs and workshops for first year students where they can practice, evaluate, and enhance their self-advocacy skills for collegiate success.

Limitations and Suggestions for Future Research

There are a number of limitations to this study. As with any qualitative research project, findings from this study are not generalizable. Study participants had a variety of non-visible disabilities. Thus, they were not representative of the heterogeneous population of students with disabilities. Participant demographics also did not reflect the racial, ethnic or gender diversity of students with disabilities. Information about socio-economic status was not collected so we are unable to explore if, or how, socio-economic status and self-advocacy were connected. Moreover, while the research team varied in ethnicity, level of education, and sexual orientation, they all identified as women.

Although grounded theory methods typically rely on intensive interviews, other data collection methods can be used. Our findings may have been enriched if we had collected data from other sources such as observations and interviews with parents and educators.

Participants reported feeling well adjusted in the college environment. While it is important to learn from students who are adapting well to the college environment, the literature suggests that this is not the experience for many students with disabilities, including many who are not registered with their campus disability offices. Future studies should include participants who successfully persist in postsecondary education with support from disability services, students who are successful *without* support from disability services, as well as those who drop out.

Our data provide evidence of the challenges students face in implementing self-advocacy in the college environment. Future research should delve more deeply into the process of learning to self-advocate in childhood and adolescence, identifying the range of skills that students bring to college and the coping mechanisms that emerge over the college years. Given the 2004 IDEIA amendment, research is needed to document the extent to which self-advocacy skills are incorporated into the IEP goals. Finally, longitudinal research could monitor student achievement of the self-advocacy goals set in the IEP over time.

Conclusion

College students with disabilities shared their perceptions about the importance of self-advocacy during their transition into college. These findings affirm the significance of teaching and reinforcing self-advocacy skills to youth well before they prepare to enter postsecondary settings. Family members and K-12 educators play an essential role in preparing youth to independently self-advocate in postsecondary education. Finally, narratives from eight students with disabilities begin to fill the gap in the higher education literature about the specific ways college students self-advocate once they arrive on campus. Our data suggest that students need the capacity to be proactive, reactive and retrospective when self-advocating in postsecondary environments.

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