

College Students With Disabilities Redefine Activism: Self-Advocacy, Storytelling, and Collective Action

Ezekiel W. Kimball
University of Massachusetts Amherst

Adam Moore and Annemarie Vaccaro
University of Rhode Island

Peter F. Troiano
Central Connecticut State University

Barbara M. Newman
University of Rhode Island

Despite rapid growth in the numbers of students with disabilities enrolling in higher education, there is limited research about their experiences in colleges and universities, and information about their collegiate activism is even more limited. Through a constructivist grounded theory study of 59 college students and recent graduates, we demonstrate the connection between activism and purpose in the lives of students with disabilities. Our findings suggest advocacy skills and activist tendencies were socialized early in life by parental role models. College students with disabilities drew upon foundational self-advocacy skills to engage in a variety of forms of disability activism during college including doing, role modeling, and teaching self-advocacy; reducing stigma through education and storytelling; and collective action. College students also engaged in activism on issues other than disability. Narratives from students with disabilities demonstrate a need to rethink traditional notions of activism in order to develop broader and more accurate definitions of college activism.

Keywords: disability, activism, self-advocacy, stigma, identity

The number of students with disabilities attending higher education institutions is growing rapidly—both in terms of raw numbers and as a percentage of overall enrollments (Snyder & Dillow, 2013). Nonetheless, we know comparatively little about their actual campus experiences (Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016; Peña, 2014). The limited information that we do have, however, suggests that students with disabilities may experience a

chilly climate (e.g., stereotypes, assumptions, exclusion) in higher education (e.g., Cress & Ikeda, 2003; Elliott, Gonzalez, & Larsen, 2011; Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010). The end result is that students with disabilities face conditions that might serve as an incentive for activism. Yet, very few scholars have studied activism among college students with disabilities.

The lack of attention to the collegiate activism of persons with disabilities has profound implications for scholarship and practice. For example, the experiences of people with disabilities are often not included in broader historical treatments of student activism (e.g., Boren, 2001; Degroot, 1998; Feuer, 1969). Yet, it is clear that disability activism has a long history (e.g., Baynton, 1996; Davis, 2015; Edwards, 2012). Equally problematic, even these histories of disability activism often understate, or do not acknowledge, the role of college students in the development of legislation designed to protect the civil rights of students with disabilities (e.g., Davis, 2015; Schweik, 2009; Scotch, 2001).

Ezekiel W. Kimball, Department of Educational Policy, Research, & Administration, University of Massachusetts Amherst; Adam Moore, Special Education, University of Rhode Island; Annemarie Vaccaro, Department of Human Development & Family Studies, University of Rhode Island; Peter F. Troiano, Counselor Education and Family Therapy, Central Connecticut State University; Barbara M. Newman, Department of Human Development & Family Studies, University of Rhode Island.

Correspondence concerning this article should be addressed to Ezekiel W. Kimball, Department of Educational Policy, Research, & Administration, University of Massachusetts Amherst, 252 Hills South, Amherst, MA 01003. E-mail: ekimball@educ.umass.edu

This invisibility may contribute to the misimpression among faculty and staff members that students with disabilities are not engaged in contemporary activism, which may in turn alter their behavior toward students with disabilities and student activists (Bensimon, 2007). It may also prevent students with disabilities from recognizing that their current activism stems from and contributes to the historical climate for diversity on college campuses (Hurtado et al., 2012). More information about the activism of students with disabilities is required to guard against these potentially deleterious effects.

In this article, we share results from a constructivist grounded theory study of 59 college students and recent graduates with disabilities. The original focus of the study from which these observations are drawn was to explore the sense of purpose among college students with disabilities. Given the limited research on the relationship of disabilities to psychosocial development in adolescence and early adulthood, we approached this work by encouraging students to give their own definition of disability, to explain the meanings they associated with their disabilities, and to describe the ways these disabilities figured into important life decisions, especially decisions about where to go to college, what to study, career aspirations, plans for after college, and long-term life goals.

Drawing on the work of Damon and colleagues (Damon, Menon, & Bronk, 2003; Damon, 2008), we think of purpose as a higher-order goal that gives direction and meaning to life. Damon et al. (2003) defined the construct: "Purpose is a stable and generalized intention to accomplish something that is at once meaningful to the self and of consequence to the world beyond-the-self" (p. 121). Building on this definition, we hoped to discover students' intentions about their goals, what steps they were taking to achieve their goals, and what if any motivations guided them to want to connect their efforts to the betterment of others (Malin, Reilly, Quinn, & Moran, 2014). Embedded in this definition is an implied potential path toward activism, sometimes referred to in the literature as civic purpose (Malin, Ballard, & Damon, 2015). Our assumption is that the sense of purpose matures over the period of early and later adolescence, as young people think about what matters to them, what they care about, and what they hope to achieve in the near and dis-

tant future. We hoped to gain a greater understanding of whether and how students' experiences with their disabilities influence their sense of purpose. From our analysis emerged important themes regarding disability activism.

Literature Review

High-quality empirical literature on students with disabilities is limited (Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016; Peña, 2014). Therefore, we made use of a variety of bodies of literature to craft this article—some focused specifically on disability, others on activism, and still others the broader experience of college students. In this section, we specifically discuss key research linking purpose and activism, review competing definitions of activism, and explore connections between identity development, activism and advocacy among students with disabilities.

Developing Purpose, Doing Activism

A sense of purpose includes a desire to achieve goals that contribute to others or to make a difference in society (Damon et al., 2003; Damon, 2008). The definition of purpose—to accomplish "something that is at once meaningful to the self and of consequence to the world beyond-the-self" (Damon, p. 121)—can also be viewed as a descriptor for activism. Indeed, some scholars have connected youth activism and purpose by using the term civic purpose which is "a sustained intention to contribute to the world beyond the self through civic or political action" (Malin, Ballard, & Damon, 2015, p. 109).

In their study of high school seniors, Malin and colleagues explicated how participants articulated varying levels of civic purpose. They operationalized civic purpose as a clear desire to be involved in a meaningful civic activity; engagement in the activity; and motivation to have an impact beyond the self through the activity. Some students had an intention to contribute but had not actively engaged or they were active but without a clear sense of how it related to a future sense of purpose. These results support the idea that an emerging capacity for activism in high school is rooted in a developing sense of purpose. Developing civic purpose in high

school may serve as a precursor to collegiate activism.

Routes to civic activism among college students may differ depending on opportunities, encouragement, and role models for active engagement (Kahne & Middaugh, 2009). Ballard, Malin, Porter, Colby, and Damon (2015) investigated motivations for civic participation among ethnic minority and immigrant youth. This study addressed the possibility that experiences of inclusion or exclusion might influence the motivation for civic activism (Lopez & Marcelo, 2008; Sánchez-Jankowski, 2002). Four motives for civic activism were identified: helping identity (e.g., I'm the kind of person who helps others); instrumental motives (e.g., to further my education); personal issues (e.g., to do something about an issue I care about); and weak motivation (e.g., it sounded like fun). Youth in both political and nonpolitical types of civic engagement were equally likely to be motivated by personal experiences and their developing sense of purpose. Students who were politically active were more likely to agree that they were upset by something they saw happening and wanted to take action to express their beliefs. This study did not include students with disabilities as a marginalized group. However, it confirms the importance of exploring how experiences of marginalization or observations of injustice in one's community can stir emotions, foster a sense of purpose in young people, and lead the way toward civic purpose and activism.

Activism, Self-Advocacy, Identity, and Students With Disabilities

For our study, we drew upon diverse definitions of student activism to understand the behaviors of students with disabilities. Ropers-Huilman, Carwile, and Barnett (2005) defined student activism as "more than just organizational involvement; instead, it implies involvement in and commitment to social change" (p. 298). In this definition, they establish a very high bar: Students are expected to identify a pressing social problem, mobilize, and seek to address the problem. However, others suggest that resistance might be a more appropriate term for student behaviors challenging the status quo. For example, Boren (2001) argued that resistance is often "historically primary to student

actions" and a response to the belief that students "are actively oppressed by the powers that be . . . and that in combating those forces . . . they are in actuality resisting aggression and suppression" (p. 4). While similar, resistance can thus be contrasted to activism based on differences in the extent to which the resultant behavior is ideologically motivated. Whereas activism is depicted as an intellectual act, resistance can be a visceral and emotional one. Importantly, elements of both activism as defined by Ropers-Huilman, Carwile, and Barnett (2005) and resistance as defined by Boren (2001) are included in Pasque and Vargas' (2014) discussion of the activism of college students with disabilities. Our article further broadens the definition of activism to include an emotional engagement rooted in larger senses of identity, stigma, and purpose as well as the concept of self-advocacy from the disability studies literature.

The connection between activism and advocacy is made throughout the larger body of literature on the experiences of people with disabilities. This broader literature suggests that disability activism has been on the rise for years and has increasingly come to shape the way that people with disabilities understand themselves and are understood by others (Rembis, 2010; Scotch, 1988). For example, young adults with developmental disabilities (Ford, Acosta, & Sutcliffe, 2013) and the culturally deaf/Deaf (Padden & Humphries, 2006) have recently used activist behavior to assert the need for self-direction. Similarly, Fine and Asch (1988) suggested that activism can serve as a catalyst for stigma reduction. However, as Checkoway and Norsman (1986) indicated, activism often requires rehearsal before an engagement in overt behavior. For many, the university can represent just such an incubator—and while fulfilling this role, the university may also be changed (Gabel, 2010; Loewen & Pollard, 2010; Lynch, 2010). In one particularly compelling and concrete example, Cory, White, and Stuckey (2010) detailed the way in which student disability identity became connected with larger political discourses and prompted student activists to force institutional change at Syracuse University.

The concept of self-advocacy is prevalent in the disability literature as well as some of the aforementioned studies of activism (Ford, Acosta, &

Sutcliffe, 2013; Padden & Humphries, 2006; Pasque & Vargas, 2014). Therefore, selected research about self-advocacy informed this project. As a concept, self-advocacy includes the ability to communicate needs and wants, locate services, and obtain necessary supports (Stodden, Conway, & Chang, 2003). Test, Fowler, Wood, Brewer, and Eddy (2005) described key components of self-advocacy as knowledge of self, knowledge of rights, ability to communicate, and ability to be a leader. Research with college students has shown self-advocacy skills are related to successful college adjustment, persistence, academic performance, and the development of a sense of belonging (Adams & Proctor, 2010; Daly-Cano, Vaccaro, & Newman, 2015; Getzel & Thoma, 2008; Hadley, 2006; Murray, Lombardi, & Kosty, 2014; Vaccaro, Daly-Cano, & Newman, 2015). Moreover, students with disabilities who understood their needs and requested accommodations in college had stronger advocacy skills and self-concepts than those who did not (e.g., Anctil, Ishikawa, & Tao Scott, 2008; Lombardi, Gerdes, & Murray, 2011; Lombardi, Murray, & Gerdes, 2012; Morningstar et al., 2010).

For students with disabilities, self-advocacy is also associated with the ability to embrace disability as part of one's sense of self (e.g., Crocker & Major, 1989; Loewen & Pollard, 2010; Markoulakis & Kirsh, 2013; May & Stone, 2010). For people with disabilities, this association likely stems from the socially constructed nature of both disability and disability stigma (e.g., Abberley, 1987; Dunn & Burcaw, 2013; Riddell & Weedon, 2014; Swain & French, 2000). That claim is also consistent with other theories of social identity development that emphasize the move from internal acceptance to societal engagement (e.g., Cross & Fhagan-Smith, 2001; D'Augelli, 1994; Hardiman & Jackson, 1997).

For example, as summarized by Hardiman and Jackson (1997) many theories of social identity development suggest that an early stage of growth includes the development of identity consciousness while later stages include overt, political engagement toward the destigmatization of that identity (Hardiman & Jackson, 1997). In an effort to show the commonalities between the identity development journeys of people from a variety of historically marginalized social identities, Hardiman and Jackson (1997) developed a model of social identity develop-

ment with stages that contained common attributes of other single identity models. Hardiman and Jackson's model also included this important process of identity consciousness, awareness, and acceptance followed by challenging stereotypes and oppression through activism. As suggested previously, these conceptualizations are quite similar to social constructionist conceptualizations of disability, which emphasize the relationships among individual, environment, and social stigma as well as the capacity of those with disabilities to contest and reframe the social production of disability (Swain & French, 2000).

Method

The main focus of our constructivist grounded theory study (Charmaz, 2014) was the development of a sense of purpose among students with disabilities during their college years. One of the hallmarks of grounded theory research is the rejection of a priori assumptions. We did, however, begin our study with a research informed understanding of the purpose which is "a stable and generalized intention to accomplish something that is at once meaningful to the self and of consequence to the world beyond-the-self" (p. 121). Grounded theorists rely on concepts that emerge from the data (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Through our constant comparative analysis process, we documented activism of college students with disabilities to be an important emergent theme. Students shared perspectives on, and manifestations of, activism in response to our questions about developing purpose. Drawing from our constructivist paradigm, we utilized those grounded and coconstructed meanings of activism to craft this article. Most notably, this article stems from the way in which advocacy, activism, and purpose were described by many of our participants as mutually reinforcing and contingent concepts. For example, when asked to relate situations that they had found troubling or to describe people and things that made their lives meaningful, participant responses often involved mixed elements of advocacy, activism, and purpose. That led us to revisit our broad understanding of purpose, which in turn led to the writing of this article.

Participants

We used grounded theory theoretical sampling to identify a diverse pool of students with disabilities who could contribute to our understanding of the development of purpose during college. Through theoretical sampling, researchers seek “pertinent data to elaborate and refine categories in [their] emerging theory” (Charmaz, 2014, p. 96). Piantanida, Tananis, and Grubs (2004) also described how theoretical sampling is invaluable for “broadening our appreciation for the complexities and nuances of the phenomenon” (p. 337). In our case, theoretical sampling enabled us to delve into the complexities of activism through the narratives of current and former students with documented disabilities as they discussed the development of their sense of purpose.

Our participants were 59 current students and recent graduates from four different institutions in three northeastern states. Participants were recruited through e-mail and word-of-mouth invitations sent via each institution’s disability services office. Students attended both private and public institutions as well as institutions of widely different selectivity levels.

All participants were asked to complete a brief survey to provide self-reported demographic information. The average age of participants was 22 years. While the primary residences of participants were in the same group of northeastern states as the institutions they attended, participants also came from mid-Atlantic and midwestern states such as Maryland, Pennsylvania, and Oklahoma. Participants were roughly evenly distributed among those living on and off campus. Forty-five participants self-identified as women, 12 as men, and two gender-queer or transgender. Forty-five students identified as heterosexual, three as lesbian, one as bisexual, two as queer, two as questioning, and six students preferred not to answer. The diversity of reported race/ethnicities of participants mirrored the institutions from which they were drawn: 49 participants reported being White; five, biracial or multiracial; two, Asian American or Pacific Islander; two, Latina/o; and one, Black.

Participants self-identified as having a variety of visible and invisible disabilities that closely mirror national university student disability data (Raue & Lewis, 2011). It is noteworthy that

42% of participants self-identified as having at least one comorbid disability and of those participants, 32% self-identified as being diagnosed with a specific learning disability and attention deficit/hyperactivity disorder (ADHD). In total, 23 participants (39%) self-identified as having a specific learning disability; 16 (27%) had ADHD; 14 (24%) had a mental health diagnosis; 9 (15%) self-identified as having a physical disability; 4 (7%) listed other health impairments; 3 (5%) listed autism spectrum disorders; 2 (3%) self-identified as deaf; 2 (3%) self-identified as blind; and 2 (3%) had traumatic brain injuries.

Procedure

Consistent with common practice in grounded theory studies focused on how a person’s meaning-making processes shape their behaviors, we used one-on-one interviews as our data collection technique (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Our semistructured interviews (Rubin & Rubin, 2011) lasted between 60 and 120 min. All interviews were transcribed and then subjected to grounded theory analysis (Charmaz, 2014). Though the semistructured interview protocol did not include explicit questions about student activism, we asked students to relate information about their development of a sense of purpose as people with disabilities. Questions emphasized their successes and challenges in life and on campus; strategies for advocating for their needs; social and philosophical commitments; and short- and long-term goals. Both direct and indirect invocations of activism appeared in response to these questions, and consequently, activism emerged as a key idea during early open coding and memoing process (Charmaz, 2014).

As noted earlier, grounded theory researchers use iterative processes for analysis (Charmaz, 2014). To do this, we revisited all transcripts with an eye toward resistance and activism and subjected the dataset to another round of inductive and systemic constant comparative analysis—documenting new open, axial, and selective codes to generate a preliminary grounded theory of activism among students with disabilities. Our analytic focus on manifestations of activism aligns with constructivist grounded theory emphasis on action and process (Charmaz, 2014).

Trustworthiness and Credibility

We used a number of strategies to ensure trustworthiness and credibility. First, we utilized analytic triangulation (Patton, 2002) where each transcript was coded independently by at least two researchers. Codes were then reviewed, compared against the corpus of data, and revised by the research team multiple times. Only after consensus among the entire research team was the coding frame finalized. Second, we used negative case analysis (Glesne, 1999) when a participant's experiences ran counter to our emergent findings. Third, peer reviews from disability scholars, educators, and students were also used to ensure credibility of our emergent themes (Jones, Torres, & Arminio, 2014).

The team addressed relational competence (Jones et al., 2014) in a host of ways. First, we utilized reflexivity (Glesne, 1999) in regard to our social identities, positionality, power relationships, and preunderstandings (Jones et al., 2014). We avoided obvious power differentials by not pairing participants with interviewers with whom they might have a teaching or advising relationship. At biweekly research team meetings, we engaged in reflexive discussions about our assumptions, concerns, and questions related to our processes, analyses, and conclusions. We also engaged in individual and collective reflection on the ways our researcher positionality may have shaped research processes and products. The five-person research team identified as members of a variety of sexual orientations, ages, religions, and social classes. Positionality specifically related to our identities and perspectives regarding ability were especially salient to this project. Barbara has a mobility disability which impacts her walking and somewhat limits her comfort in exploring new environments. In this regard, she is particularly sensitive to the narratives in which students describe challenges they face regarding transportation, access, the layout of buildings, parking, and managing the physical demands of the environment. Ezekiel also identifies as a person with a disability—having been diagnosed with obsessive-compulsive disorder at an early age. Additionally, in his prior professional role, he was responsible for coordinating disability services for a small college. Adam does not identify as a person with a disability, but is a special education teacher by training, an

expert on disability law, and has worked with persons with disabilities in prekindergarten–16 settings for more than 15 years. Annemarie does not identify as having a disability. She constantly reflected on possible unconscious a priori assumptions rooted in prior studies about student activism she conducted with other marginalized populations. Peter's close connection to the topic of disability stems from having a younger sibling with a learning disability. Seeing his sibling struggle inspired his doctoral work on college students with learning disabilities. Peter has been employed at two small private colleges with specialized programs for students with learning disabilities.

Findings

Our iterative grounded theory analysis led to an expansive view of activism among students with disabilities. We found activism manifested in a range of behaviors that fit into three overarching themes. Our first main theme shows students learned basic advocacy skills from parents early in life. This socialization process inspired participants to do activism before and during college. To explicate the second emergent theme of collegiate disability activism, we highlight three subthemes: (a) doing, role modeling, and teaching self-advocacy as activism; (b) reducing stigma through education and storytelling; and (c) collective action through formal organizations. Our third theme reflects students' desires to engage in activism about a host of topics—not only disability. Students were more than their disabilities and their activist efforts reflected that reality. A part of their journey as activists included coming to understand themselves not just as people with disabilities, but also as people who are more than their disabilities. That process of identity development is often catalyzed by recognition and confrontation of the stigmata associated with disability, which in turn may become the focus for student activism.

Learning Activism Early

From our interviews, we learned that activist training began early in life. Students were socialized by parents who not only advocated on their behalf, but also taught them advocacy skills. According to many participants, it was through these interactions that they first

learned they had a disability. They were also socialized to think about disability as an important part of their identity. This burgeoning disability identity coupled with advocacy skills translated into forms of precollegiate activism where students advocated for themselves and peers with disabilities.

Many of our participants learned about the importance of activism by watching parents fight for their rights with the school system. By witnessing parents demand accommodations and access, students with disabilities learned that advocacy skills were essential life skills. Ida's mother challenged school decisions rooted in disability stereotypes and stigma such as Ida not being "bright enough" to do college preparatory courses. Ida explained,

They kept trying to tell my mom, "Oh, she just needs to go to a career in tech." My mom was like, "No, do you see how smart she is? She's going to college. She's going to make something of her life, and you can't tell her otherwise."

Fanny also told stories about her mother's activism. With multiple children with disabilities, Fanny's mom was constantly advocating to ensure all their needs were met. Fanny explained,

She went to the school system. She's like, "You need to accommodate that." . . . My mom would always get her way no matter what. If my brother . . . was denied accommodations because they didn't feel like they were necessary, my mom did not like that. She made everyone know she did not like that and . . . later that year she was on the school board. Like one of them was retiring or something, she was just put on the school board . . . I do not even think there was [an election]. I think she just [said], "I'm going to do this and you can't stop me." Nobody was willing to.

Through her mother's activist efforts, Fanny learned how important it was to stand up for herself and others. For Fanny, this early lesson helped to pave the way for disability to become a part of her identity. Similarly, by witnessing her mother bring a civil rights lawsuit against the school district, Erin gleaned important lessons about advocacy for self and others.

Our participants were not merely watchers. Many began to take the reins and self-advocate at very young ages. In the following quote, Willa explains how she demanded legal accommodations she was due during high school. She described her self-advocacy and

the resistance she got from school administrators as follows:

[I said] "You know you still have to make these enlargements because it's the law." And they said, "well we know that." . . . So um, yeah they eventually sat me down after and said "You know there's an order of command for a reason basically, and you went above everybody straight to the top." And I kind of went "Well that's nice, I'm glad you have your opinion, but this is my education. . . . And I'm not going to stop until I make sure I get what I need, and you know if that's, if I know what I need to be successful then I'm not going to stop until I get it." I guess, that's what kept me going.

Like Willa, many of our participants began to self-advocate for services and support well before arriving at college. We contend these forms of self-advocacy were indeed manifestations of activism.

In the process of learning to self-advocate, many young people realized advocacy skills were transferrable and could be used to support and educate others. Self-advocacy is rooted in knowledge of, and education about, disability diagnoses, disability rights, and services (Stodden, Conway, & Chang, 2003; Test et al., 2005). Our participants built upon this foundation by incorporating education into their precollege activist efforts. Willa explained how a guidance counselor invited her to put her advocacy skills and knowledge about disabilities to work as part of a plan to stop school bullying. She shared, "In elementary school . . . I talked about albinism. . . . It kind of broke those barriers and that bullying stopped." In high school, Peter's activism included educating preservice teachers about dyslexia. Through this activism, he hoped to make schools better places for students with disabilities. Peter shared,

I was a student advocate so I actually gave speeches at other colleges while in high school on dyslexia. We went to people who wanted to go into the special education field and we just talked to them about like what dyslexia was and what like myths about it and like other aspects about it.

In summary, college students with disabilities explained how they learned advocacy skills early in life from activist parents. Through the socialization process, they learned to self-advocate. Many also began applying basic activist skills to precollege activism in the form of education.

Disability Activism During the College Years

Through our analysis, we came to see how disability activism manifested in three ways during the college years. First, collegiate activism, like precollege activism, included advocating for self and others. By the time they reached college, our participants recognized that while advocating for others was necessary, it was equally important to role model and teach others self-advocacy skills. The second aspect of collegiate activism included debunking stereotypes about disabilities and reducing stigma by educating through storytelling. Our participants raised awareness about disability topics and challenged misconceptions through stories about their disability. Third, collegiate activism sometimes involved participating in disability advocacy organizations on and off campus.

Doing, role modeling, and teaching self-advocacy as activism. Almost all of the students had to self-advocate for accommodations at some point during their college career. Sometimes this was because disability services did not agree to a particular accommodation, a professor disregarded documented accommodations, or a particular campus environment was not conducive to their needs. Students also had to advocate for themselves in other realms of life (e.g., with doctors, employers) in order to be successful college students. Sometimes that involved challenging the negative perceptions and stigmata held by those in positions of authority. For instance, they needed to be healthy in order to focus on schoolwork. Olive self-advocated with her doctor after feeling frustrated about her treatment which seemed to be hindering her ability to focus on academics. She reflected,

I felt like I was not being supported by my psychiatrist a couple weeks ago so I actually decided to stop taking my medication and cancel all my future appointments. I've been a lot better since then. It's amazing . . . the medicine was making me unfocused it was making me like really incapable of things. . . . He goes, "I don't understand how you think it's the medication." And I was like, "I don't understand how you claim to be looking out for my best interest."

Similarly, Layla took her self-advocacy to the courts when she was being discriminated against because of her disability and form of treatment. Like many of her peers, Layla needed

to earn money to cover the cost of college. She explained,

I'm in the medical marijuana program. That works well for me, but it's caused some difficulties in finding employment. Because even though [this state] says you're absolutely not allowed to discriminate for that purpose, I am currently involved in a lawsuit because of somebody doing just that. . . . They flat out told me they wouldn't hire me for that reason, which is actually kind of a good thing, because they didn't try to cover it up with something else.

While she was not explicit about helping others in the prior quote, Layla's lawsuit could potentially help other students with disabilities who come after her. In fact, several of our participants recognized visible self-advocacy could benefit other students with disabilities facing similar situations. Therefore, role modeling self-advocacy became a form of activism where students were standing up for themselves while simultaneously fighting for the rights of others who came after them. As Alice explained,

You have to pave the way for the next group. . . . Even if something is not right, it's always been my experience that professionals do not always stand up and advocate for the students. [I want to] be somebody who can advocate in an honest way and help pay it forward.

Elisa's experience trying to study in a noisy residence hall led her to see how her persistence in establishing "silent" public spaces for herself could directly help future students. She viewed herself as providing a voice for other students with disabilities who might face similar experiences. Elisa shared, "If somebody with a disability needs like the quiet space, they won't speak up. So, I have to be like the person that speaks up and I'll figure out a way to do that." Nancy explained how self-advocacy was intricately tied to her desire to help others. She explained,

I've gone all throughout school, all throughout life, with these learning disabilities, so internally, I've had to be like, "I need to make myself do this," or, "I need to reach my goal by this." . . . Having those learning disabilities [is] a challenge, it makes me stronger for other people too. . . . I want to make a difference in people's lives.

Nancy used her ability to self-advocate as a catalyst for activism to help others and, in turn, activism made her "stronger too."

As collegiate disability activists, our participants drew deeply upon self-advocacy skills.

They recognized how important it was to advocate for themselves. They also believed they were in a unique position to teach others with disabilities how to self-advocate and persevere. Willa explained how she teaches “students about their disability and self-advocacy.” In addition to talking generally about teaching self-advocacy skills, Willa specifically taught college peers to self-advocate for funding. She shared, “I’ve been on the scholarship committees. . . . So I’m very well versed. . . . I’m really all about trying to get people with disabilities what they need and teach them how to get it themselves.”

Rhonda’s volunteers at a hospital where her activism includes teaching young people with disabilities how to persevere. Rhonda reflected,

She was in a wheelchair when I met her. So then I tried to make it a game. I’m like, “Okay, Maria, let’s walk around.” And she’s like, “I want my wheelchair.” And I was like, “But walking’s fun. Let’s just walk to get chocolate milk.” She loves chocolate milk. . . . And by the end of the week she was walking and she didn’t need the wheelchair. And her parents never thought she’d be out of it. . . . When the girl was leaving the hospital [her mom] was like, “Thank you, cause I don’t think we would have made it here.” Which is like a big thing . . . I motivated her.

Yolanda’s passion for teaching others to self-advocate evolved into a form of Internet activism. She explained how she writes blogs in hopes of inspiring parents to teach their children to self-advocate. She said,

My blog ranges from explaining [autism to] like answering questions from parents. . . . I want you to teach your children the skills that they need, the skills that they will need as they grow up into autistic adults instead of you trying to teach them to stop being autistic because that second one isn’t going to work.

Like many of our participants, Willa, Rhonda, and Yolanda used their own experiences as a springboard to role model and teach others how important it was to self-advocate and persevere despite obstacles. In summary, doing, role modeling and teaching self-advocacy were forms of college disability activism.

Reducing stigma through education and storytelling. Participants also engaged activism via informal and formal education about disabilities in general, and their disability in particular. Activism often manifested through educating individuals, groups, or the campus

community about disability topics to reduce stereotypes and stigma. This form of activism typically involved students sharing stories and being publicly open about their disabilities. For instance, Willa discussed how teaching others about her magnifiers helped “break the barriers of people to just become knowledgeable of people’s differences,” and in particular people who are partially sighted. Similarly, Alice described her activism as raising awareness about disabilities through storytelling. As Alice explained,

No matter what I do to help people with disabilities, I help advocate for them [by] rais[ing] awareness about issues that they go through. . . . When I talk to people and I share my story, I think about the little girl who maybe just started school, or the young man who is in high school and trying to make his way, or maybe somebody that’s in college or is just losing their sight and do not know how to navigate the system.

Participants typically had to disclose their disability in order to tell their stories. Rhonda embraced her disability as part of her identity and situated herself as an activist through “spread[ing] awareness” about her disability. Rhonda described how she disclosed when people asked about her disability.

When people ask me they’re like, “I don’t want to like make you feel uncomfortable, but can I ask questions?” And I’m like, “It doesn’t make me feel uncomfortable. It’s a part of me. It’s something I want to share.” . . . It’s not something to be embarrassed about. It’s just something I have . . . something I have to accept and appreciate.

When referring to not being “uncomfortable” or “embarrassed” about her disability, Rhonda was referencing a larger social context where disability stigma and stereotypes abound.

Many of our participants used educational interventions and storytelling as activism to debunk stereotypes and resist stigma. Reyna used a combination of storytelling and inspirational messages to counteract stereotypes about people with disabilities being less capable or even helpless. Reyna conveyed the following message through her activist work:

You can do anything you set your mind to. . . . I feel like society really likes to force [the idea] that disabled people do not go into science. They cannot do science because either A). They’re not able to physically or B). They’re not able to mentally. I’m here to prove that wrong.

Erin was passionate about challenging stereotypes about mental illness. Through activism Erin tried to send the message that,

just 'cause you're anxious and have some sort of mental illness, doesn't necessarily mean you won't go places. You don't have to be stuck in this bubble. If you can pop bubbles, you can go as far as anyone else can.

For her, activism included debunking stereotypes, being proud of her disability, telling her story, and teaching others to be proud of themselves.

Seeking collective action through formal organizations. In previous sections, we exemplified how students engaged in activism through self-advocacy and educating others. Sometimes, these young activists sought clubs and organizations as venues for collectivist disability activism. Unfortunately, not all campuses in our study had active disability organizations. Or, when they did, students like Willa did not feel connected with group members or agree with the focus of the group. Willa shared,

I was extremely active on campus during all four years that I lived on campus. I was in the disability advocacy [club]. Unfortunately there were some people in the disability advocacy club that didn't share the same vision that I had about people with disabilities and they weren't exactly giving executive board positions to people that were capable of doing the position. I didn't believe in what they were doing anymore so I left.

Similarly, Yolanda could not locate an activist group on campus focused on autism spectrum topics, which were her passion. She said, "On campus, I don't really do much of anything because the autism organizations don't have anything to do with campus." Like many of her peers, Yolanda was forced to seek disability activist communities off campus. In her quest to find outlets for her activism, Yolanda researched state and national organizations such as Autism Self-Advocacy Network, and Autism Woman's Network—none of which fully met her needs. Other students found sites for collectivist activism in community organizations. For instance, Carl served on an autism board and Willa was a member of a youth leadership project in their home states.

Activism Beyond Disabilities

Activism is often rooted in a person's sense of purpose, identities, and passions. In the prior

sections, we described roots and manifestations of disability-specific activism. However, students were more than their disabilities. Our participants talked about activist work inspired by other social identities, interests, and life purpose. Sometimes, these activist efforts had little or nothing to do with their disability. For instance, Tessa was passionate about activism that supported local youth of color. Isaiah described himself as a lesbian/gay/bisexual/transgender (LGBT) activist. During college he also became active in a service fraternity where he engaged in activism around a host of social causes. He described his passion for serving others as a way to live his activism. Isaiah shared, "We're a community service fraternity. It attracts a good kind of person who just likes helping other people and likes doing things to help make the world a better place."

Some students used personal life experiences and struggles as an impetus for activism. For instance, Betsy suffered severe injuries in an automobile accident in the summer just before starting college. Her activism included giving talks to high school students about her experiences. She hoped to encourage teenagers to make the decision not to drive while intoxicated. She explained, "I basically almost died. . . . I want to influence like good . . . decision-making. I don't want anyone to suffer what I suffered and I don't want people to die. I don't want people to be incapacitated." While these talks were inspired by her accident and physical injuries, the focus of her activism was on drunk driving, not her disability per se.

Liza described how she volunteered with a grief group for children who lost relatives or who had a family member with a terminal illness. This opportunity was particularly meaningful after losing her mother as a child. Liza drew upon her activist skill set to teach others how to cope with and persevere through loss. She shared,

Grief is really close to me. These kids are losing [parents] or their parents died or their sister died. I work with 12 year olds that had their parent die when they were seven. It's really close to home, but I'm not sad. I feel good. I feel fantastic when I leave.

Other participants described passions for the environment, animals, or fighting poverty. Reyna shared,

One of the things that I do love is advocating . . . for those that don't have a voice such as wolves. You know I think it's a real tragedy when wolves get killed and animals get killed just because someone doesn't know about it.

This passion prompted Reyna to become a member of an activist organization called the Yellowstone Wolf Project. Hazel's developing sense of life and career purpose led her to an environmental major and a variety of opportunities for environmental activism. She shared,

With the environmental science major, that'll put me right into the environmental movement. Actually I was a canvasser for Oxfam last summer and that was like an activist kind of a job. Starting on Sunday I am going to be a canvasser for the Sierra Club. So again that is already getting me into the green movement.

Bree shared several passions that drove her activism around serving those in need. She said, "I volunteer a lot whenever I get a chance, whether it's a hospital back at home over the summer, or here [near campus]. Whenever I get the chance, [I do] Habitat for Humanity." In summary, college students were more than their disability and so was their activism.

Discussion

Implications

As Kimball, Wells, Ostiguy, Manly, and Lauterbach (2016) noted, the literature on students with disabilities is both sparse and poorly connected to literature on other student populations. Our findings are meaningful both because they shed new light on an understudied population and also because they tie into a well-established body of literature describing college students more generally. More specifically, our findings (a) situate the activism of college students with disabilities within the context of developing purpose and the socialization process; (b) resist the tendency to conflate all the experiences of all people who hold a given identity and assume they will engage in collective action; (c) expand existing definitions of activism; and (d) provide the basis for concrete recommendations that will lead to a variety of positive outcomes—both in terms of activism and in terms of student success.

Even though this special issue is dedicated to collegiate activism, we found an accurate story of college activism could not begin in the ivory

tower. Collegiate activism emerged as a salient theme related to the developmental process of developing a sense of purpose. While developing purpose is an essential outcome for college students (Chickering & Reisser, 1993), the process of constructing higher-order goals that give direction and meaning to life begins much earlier in life (Damon et al., 2003; Damon, 2008). Also, activist roots began well before college when participants were socialized by parents to value, and participate in, advocacy for self and others.

Colleges and universities often partner with kindergarten–Grade 12 (K–12) schools for tutoring and mentoring programs. Another area for potential collaboration is cultivating and supporting collaborations among students with disabilities. Even though our participants seemed to have parents who taught them to self-advocate, we know this might not be a reality for all students with disabilities. In fact, Yolanda lamented how many parents of children with autism were not teaching them to self-advocate. By connecting students with disabilities across the educational spectrum, we may be offering a valuable opportunity for students with disabilities to learn self-advocacy skills and practice activism from each other.

Students with disabilities are not a homogeneous group and their varied forms of activism reflect their heterogeneity and diversity. Vast differences in disability diagnoses, student needs, and identity development can be a hurdle for collective interests and activism. For instance, students on the autism spectrum, students with anxiety, and deaf students might have very different needs and corresponding ideas for collective action. From an administrative perspective, confidentiality issues, combined with the prevalence of invisible disabilities, create additional logistical challenges for collective action among college students with disabilities. Therefore, educators should not assume that an absence of collective action reflects an absence of desire. Lack of collective action may, instead, be a result of logistical challenges, diverse disability diagnoses, or ideological differences among students with disabilities. Checkoway and Norsman (1986) argued that effective activism requires rehearsal. As such, K–12 and higher education institutions should consider the creation of safe spaces for students with disabilities to rehearse activism.

Creating opportunities for students with disabilities to connect across the K–12 and higher education divide may also solve the problem encountered by many of our participants—the lack of collective disability activist groups on campus.

Another important theme that emerged from this study was that student activists with disabilities are more than their disability. Drunk driving, the environment, animal rights, racism, LGBT issues, and poverty were activist passions connected to our participants' developing sense of purpose. These results remind professionals not to assume students with disabilities only want to engage in activism around disability topics. This assumption tokenizes them and limits their ability to be whole people with a variety of passions and interests. Participants often engaged in collective action through formal activist organizations (e.g., Yellowstone Wolf Project, Oxfam, Sierra Club) and drew upon skill sets learned and honed through all types of collegiate disability activist behaviors (i.e., self-advocacy, storytelling, collective action).

Our findings expand existing definitions of activism that tend to emphasize only collective action. The specific way in which each student engaged in activism varied. For some, being a strong self-advocate felt best while for others finding a group connected by shared experiences proved most meaningful. The expressed desires for collective disability activism as well as collective action with formal activist organizations (e.g., Yellowstone Wolf Project, Oxfam, Sierra Club) coheres most closely with prevailing notions of student activism. However, advocating for self and others in the context of societal stigma is also a form of resistance. Taken together, the three manifestations of collegiate disability activism (self-advocacy, storytelling, and collective action) reflect traditional images of activism (Ropers-Huilman, Carwile, & Barnett, 2005) and resistance (Boren, 2001) expressed in earlier writings.

Our findings also connect disability identity and disability stigma to student activism. They begin to suggest the extent to which the same processes implicated in the activist behaviors of students identifying with other historically marginalized social identities may also be operational in experiences of students with disabilities. For example, awareness of one's disability

is an important context for activism in our study. Simply put, it is hard to advocate for others without an understanding of oneself. In models of identity development, awareness is also a precondition for a stronger sense of self (Hardiman & Jackson, 1997). Likewise, models of collective action often suggest recognition of group membership as a precondition for political engagement (Han, 2009). In the case of students with disabilities, activist behavior is often intended to reshape prevailing social stigma toward those with disabilities. Our findings suggest that part of the process of becoming aware of one's disability and the need for advocacy is learning about those social stigmata so that they can be challenged.

Focusing on self-advocacy as a means to foster activism among students with disabilities is likely to have positive effects in other regards as well. Activism in our participants emerged from watching parents advocate for their children's rights. Through their socialization process, young people with disabilities learned the importance of, and skills to, advocate for self and others. Yet, learning to self-advocate was more than mere skill building. Student activism (before and during college) was deeply rooted in doing, role modeling, and teaching self-advocacy. As such, it is important for educators, administrators, and parents to understand the significance of self-advocacy.

Higher education professionals in particular should learn to recognize and support students' efforts at self-advocacy. Some professionals might view demands for services or rights as entitlement. By looking deeper into a student's situation, professionals may find that students with disabilities are engaging in a form of activism to get their own needs or the needs of others met. Prior research suggests self-advocacy skills are related to successful college adjustment, persistence, academic performance, and the development of a sense of belonging (Adams & Proctor, 2010; Daly-Cano, Vaccaro, & Newman, 2015; Getzel & Thoma, 2008; Hadley, 2006; Murray, Lombardi, & Kosty, 2014; Vaccaro, Daly-Cano, & Newman, 2015). Our findings support prior literature that suggests ties between self-advocacy (or the desire for self-direction) and activism (Ford, Acosta, & Sutcliffe, 2013; Padden & Humphries, 2006; Pasque & Vargas, 2014). These connections between self-advocacy and activism make sense since self-advocacy is built upon factors such as knowledge

of self, knowledge of one's rights, the ability to communicate effectively, and leadership skills (Test et al., 2005). All of these abilities are important for students generally and activists specifically.

Limitations

There are a number of limitations to this study. First, we did not begin our study with a narrow focus on activism. Instead, manifestations of activism emerged through our interview questions about identity, obstacles, campus experiences, and the development of a sense of purpose. Had we begun the study with an explicit emphasis on activism, different findings may have emerged. Nonetheless, we are confident that our constructivist grounded theory process (Charmaz, 2014) allowed valuable images of activism to emerge and further that the relationship between activism and purpose emerges more clearly from our study than it might otherwise.

Second, our sample was not very diverse by gender, race, or even type of disability. However, our large numbers of women and White students was reflective of the campus demographics of the institutions our participants attended. Likewise, learning disabilities, ADHD, and mental health issues are the most common types of disabilities reported on the campuses where we worked—as they are on college campuses nationwide (Snyder & Dillow, 2013). Overall, the lack of diversity in our sample may also stem from the fact that we collected our data exclusively at institutions in the northeast United States. Findings may well display regional variation associated with changes in demographics. Future work that explored disability as one element of a broader intersectional production of self—along with social identities such as race and gender—would be particularly meaningful.

Third, this study does not systematically address the interrelationships among disability, activism, and socioeconomic status. Previous research has demonstrated that socioeconomic status does play an important role in mediating the experiences of students with disabilities (Kimball, Wells, Ostiguy, Manly, & Lauterbach, 2016) and in predicting activist behavior (Han, 2009). However, our findings regarding socioeconomics were complicated by limited

participant awareness of parental income and by discomfort with the idea of social class. Future work will explore these findings in detail, but this study does not distinguish between students based on social class.

Finally, our study relies exclusively on student reports of experiences and identities. While this focus is appropriate given our interest in a student's sense of purpose, the use of institutional data such as student records or interviews with campus personnel might have yielded different information. Future research examining the interface between the experiences of individual students and campus structures might help to demonstrate why some students make the decision to engage in more traditional forms of collective activism while others do not.

Conclusion

Our findings suggest existing conceptualizations of student activism do not fully appreciate the experiences of students with disabilities. Scholarship on students with disabilities has typically divided research into separate categories of self-advocacy, activism, stigma, or identity. By developing an understanding that takes into account all of these disparate areas of scholarship, as well as the importance of early socialization, our work can lead to a more holistic understanding of activism for college students with disabilities. Importantly, our findings emphasize that students with disabilities are indeed activists—filling gaps in the higher education activism literature and historical documents about the disability rights movement that offer cursory mention of college students with disabilities, or exclude them altogether.

Students with disabilities often learned self-advocacy skills from parents early in life. These skills are essential in order to navigate the bureaucratic, medical, and legal requirements associated with the documentation of disability. They are also often the basis for broader activism. For many of our participants, day-to-day life offered ample opportunity to engage in activist behaviors. For example, while not included in many definitions of activism, students with disabilities reported that they consistently challenged stereotypes, provided role models for other students with disabilities, and sought to help others become self-advocates. Each of these actions began to erode longstanding social

stigma associated with disability. That process was deepened further when students with disabilities made the decision to share their experiences more publicly and proactively. Notably, much of this work was driven by individual students with disabilities. For the participants in our study—unlike the dominant narrative about what activism looks like—collective action is less common.

As a result, our work suggests that higher education professionals need to expand their understanding of what activism looks like to include collective action as well as independent action by students with disabilities. This reframing may be especially important since professionals often consider student activists when awarding scholarships, granting leadership awards, and hiring for campus leadership positions. Students with disabilities conducting individual forms of activism (e.g., self-advocacy, education/storytelling) should not be excluded from these opportunities.

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