

Redefining and Reconceptualizing Disability Identity in Civil Engineering

Abstract

Disabled people continue to be significantly underrepresented and marginalized in engineering. Current reports indicate that approximately 26 percent of US adults have some form of disability. Yet only 6 percent of undergraduate students enrolled in engineering programs belong to this group. Several barriers have been identified that discourage and even prohibit people with disabilities from participating in engineering including arduous accommodations processes, lack of institutional support, and negative peer, staff, and faculty attitudes. These barriers are perpetuated and reinforced by a variety of ableist sociocultural norms and definitions that rely on popularized tropes and medicalized models that influence the ways this group experiences school to become engineers.

In this paper, we seek to contribute to conversations that shape understanding of disability identity and the ways it is conceptualized in engineering programs. We revisit interview data from an ongoing grounded theory exploration of professional identity formation of undergraduate civil engineering students who identify as having one or more disabilities. Through our qualitative analysis, we identified overarching themes that contribute to understanding of how participants define and integrate disability identity to form professional identities and the ways they reshape and contribute to the civil engineering field through this lens. Emergent themes include experiencing/considering disability identity as a fluid experience, as a characteristic that ‘sets you apart’, and as a medicalized symptom or condition. Findings from this work can be used by engineering educators and administrators to inform more effective academic and personal support structures to destigmatize disability and promote the participation and inclusion of students and colleagues with disabilities in engineering and in our academic and professional communities.

Introduction

Scholars in the field of Disability Studies describe disability identity as a fluid identity consisting of a broad range of cognitive, bodily, and sensory differences and capacities that can be acquired by anyone at any time [1]. Various groups within the disability community have claimed the disability label and use identity-first language (e.g., disabled person) as a form of empowerment, liberation, and advocacy to dismantle extant oppressive structures [1, 2, 3, 4]. At the same time, scholars are shifting from language with an ableist emphasis (e.g., able-bodied) to an emphasis that centers disability (e.g., non-disabled) in ways that reflect on the fluidity of disability; that is, one is non-disabled until they are disabled [1, 4]. Such perspectives center individual personhood and lived experience of people with disabilities, highlight the diverse nature of disability, and position accessibility and inclusion as ethical necessities that a society is responsible for. These perspectives contrast those often used in the social, physical, and bureaucratic structures that shape the lived experiences of people with disabilities [5]. Such structures tend to rely on

medicalized models that describe disability as a condition to be treated and/or accommodated using a set of prescribed approaches regulated by policy [6, 7].

Conceptualizing and operationalizing disability through a medicalized lens simplifies, minimizes, marginalizes, and stigmatizes the experiences of students and colleagues in our university systems. In this paper, we contribute to conversations that redefine disability identity and the ways it is conceptualized in engineering programs. Specifically, we ask the following research questions: 1) How do civil engineering students define their disability identity? and 2) How do these definitions influence the saliency of disability identity in civil engineering? To answer these questions, we qualitatively analyzed semi-structured interviews as part of a larger grounded theory exploration of professional identity formation in undergraduate civil engineering students with disabilities. From this work, we examine the ways participants' sociocultural contexts and personal experience inform how they consider and identify with disability and civil engineering and the ways they reshape and contribute to the civil engineering field.

We recognize the ongoing debate throughout scholarly literature and daily discourse surrounding the use of person-first and identity-first language to describe disability [8, 9]. In our work, we tend to use person-first language reflecting current disciplinary and higher education norms and as demonstrated in legislation such as the U.S. Americans with Disabilities Act (1990) and the United Nations' Convention on Rights of Persons with Disabilities (2008). Yet, we also emphasize that language preferences vary among members of the disability community and affirm the ways disability activists have reframed disability as an identifying adjective to assert themselves as disabled people [3]. Therefore, we use the language choices of our participants where appropriate to remain true to their identifications.

Barriers to participation in engineering

The low number of students identifying as disabled or as having a disability in engineering programs is one reflection of marginalization. While current statistics report that approximately one in four, or 26 percent of, US adults have some form of disability, only 6 percent of undergraduate students enrolled in engineering programs identify as belonging to this group. Prior work in this area has identified several barriers to participation for students with disabilities in engineering, including lack of institutional support, inaccessible learning environments, and negative faculty and staff perceptions [5, 10, 11, 12]. To receive necessary support for academic success, students must navigate arduous and expensive accommodations procedures, which include obtaining an official diagnosis from a doctor or specialist. In the event that a student qualifies for and receives accommodations, they then must navigate social stigmas and stereotypes attached to using accommodations as an engineering student [5, 6, 10]. For some students, navigating and managing this process – in addition to daily tasks as a college student – is too emotionally, physically, and financially draining, and they opt to continue in their programs without this support [13]. These experiences with systemic barriers create personal barriers for students such as lowered self-efficacy, persistence, and sense of belonging among their engineering peers and hinder engineering identity development [10, 14]. Inherent to the

systemic and personal barriers identified throughout the literature is the variety of ableist sociocultural norms and definitions of disability that influence the ways these students experience school and become engineers [6]. In the present paper, we advocate for a paradigm shift that redefines and repositions disability in engineering in ways that more accurately represent its fluidity and diversity and promote the systemic and social inclusion of disabled community members in this field.

Sensitizing Concepts

In the present study, we utilized three sensitizing concepts to facilitate our exploration: 1) Social Identity Theory [15, 16]; 2) the Multiple Dimensions of Identity Framework [17]; and 3) disability models [18, 7, 19]. These concepts allow us to account for our prior knowledge related to identity and disability research while remaining open to unanticipated concepts and analytical relationships that may emerge from our study context and participants.

First, Social Identity Theory (SIT) captures the ways individuals partially define who they are by comparing and evaluating the values, norms, and statuses within and across social groups they choose to associate and be associated with. This theory posits that social identity cannot be constructed through “isolated individual processes or interpersonal interactions alone” [20], but rather that these systems reciprocally work together. In this study, we utilize social identity theory to think about how individuals position themselves and are positioned by others within disability and civil engineering communities and groups.

Second, the Multiple Dimensions of Identity describes personal identity as a core, unchanging sense of self that is continuously influenced by identity dimensions that become more or less salient as an individual makes meaning of their experiences. In the context of this study, we refer to identity salience as the relative influence of disability and professional identities on an individual’s core sense of self in a given context.

Lastly, we draw from concepts captured in three models of disability: the medical, the social, and the social-relational models. Each model provides a lens for defining and conceptualizing disability as well as allocating responsibility for accommodation, intervention, or locus of change (e.g., the individual, an institution, social norms, etc.). In the medical model, disability is perceived as an impairment that must be cured, accounted for, or accommodated so that individuals can either obtain a dominantly accepted sense of normality or be excluded [7]. The social model of disability focuses on the political and social structures, expected norms, and physical environments that create or construct disability as a person interacts with the world [21]. The social-relational model positions disability as generated through relationships that are controlled and constrained by social structures and actions [22]. In many instances the social-relational model overlaps with aspects of the medical model and the social model to capture the lived experiences of participants with disabilities as they interact with the world around them. A summary of the disability models is shown in Table 1 (for in-depth descriptions and examples of each model, see [23]).

Table 1: Summary of Models of Disability (from [23])

| Disability Model | Positions Disability as... | Focuses on... |
|-------------------|--|---------------------|
| Medical Model | a condition to be treated or cured | The Individual |
| Social Model | created through interactions with environment | The Environment |
| Social-Relational | interpreted through interpersonal interactions | Social Interactions |

Methods

To gain deeper insights into how civil engineering students define and experience disability in civil engineering, a series of semi-structured interviews were conducted with 30 students as part of a larger grounded theory study exploring the professional identity formation of undergraduate civil engineering students with a wide range of disabilities. Details on data collection including participant recruitment as well as semi-structured interview content and length are included in [14]. Aligning with grounded theory techniques, interview transcripts were analyzed using open and focused-coding to identify discursive indicators of participants' disability definitions as well as their recollection of significant civil-engineering related incidents that shaped those definitions. We considered civil engineering-related incidents to be any event, relationship, or experience participants described as part of their conceptions of civil engineering and while navigating their civil engineering program. Overall, we identified three overarching themes that capture how participants define their disabilities and the ways these definitions influence disability identity saliency as they experienced their undergraduate civil engineering programs.

Theme 1: Describing disability identity as a characteristic that 'sets you apart'

The first theme we identified in our analysis captures the ways participants conceptualized disability as an exception to normative or status quo ways of being. When asked if he considered himself as disabled, Fernando, who identifies as having a stutter, explained, "I don't. [. . .] I guess, on a smaller scale, I feel like a lot of people with or without stuttering, they have a hard time communicating and expressing themselves." Here, Fernando bases his disability identity definition on the extent to which individuals can effectively communicate with others. Because difficulty expressing oneself can be conceptualized in a variety of ways (e.g., due to a disability or poor communication skills, in general), Fernando does not consider his disability identity as something that sets him apart from other people.

Similarly, Deena describes how she does not position her attention deficit hyperactivity disorder (ADHD) as a disability. When asked if she thought of herself as being disabled, Deena replied, "Not really, because I feel like a lot of people have ADHD, so it's something that I feel like a lot of people don't talk about if they have it. [. . .] I don't really think of it as something that sets me apart from other people all the time." Because both Deena and Fernando conceptualize disability as an uncommon characteristic that separates disabled and non-disabled people, neither of them strongly identifies with disability as a dimension of their identities.

Theme 2: Describing disability identity as a fluid experience based on iterative comparison

Many of the participants in our study discussed their disability identities not as a medicalized label nor using formalized terms. Rather, they described their disability identity as a fluid experience contingent upon the context they were engaging in and the prevalence of their symptoms. When asked if she considers herself to be disabled, Sammie, who identifies as having attention deficit hyperactivity disorder (ADHD) explained,

I mean, in some cases, I do, but in some cases, I don't. Because I know people on campus that have more challenges than I do, both physically and mentally. But then, I also know people, I have a ton of neurotypical friends that have it easier, that don't have to worry about when they're going to take their meds, so that they can make sure that they're still feeling the effects during their 8 PM test. Or making sure that they're on time for accommodations, and stuff like that. [. . .] I don't think I've ever really said that I'm disabled, but I say that I have a learning disability, or that I need extra time on tests.

Here, Sammie also begins to demonstrate an iterative process of comparisons that participants make between their experiences with disability and the experiences with disability that they perceive others to have. For many participants, engaging in a variety of individuals and contexts, helped them develop and make sense of their disability. Skywalker, who identifies as hearing impaired with Attention Deficit Disorder (ADD) and Asperger's Syndrome, also highlighted instances where his disability identity became less salient in school because of the resources and support structures he established at his university. When asked if he preferred the interviewer to use another term instead of 'disabilities' during his interview, Skywalker stated:

Uh, I don't really care. Although I understand that some people don't like it because I do feel like I'm not disabled because I have equipment to help me, and that I can still carry out things I can do just like anyone else would be able to. So, I really don't have a preference.

Skywalker further described having supportive instructors and teaching assistants (TAs) who easily adapted to his needs. Here, he focuses his disability identity on the tools and other resources of support he utilizes in his academic program. At the same time, he discussed the difficulty of affording hearing aids as a college student and navigating the medical processes necessary to obtain that support. Sammie and Skywalker's interviews emphasized the important role of individual accommodations in supporting students during their college careers. At the same time, they also highlighted the significant influence of context and the individuals they engage with in those contexts to inform how they identified with disability.

Theme 3: Describing disability identity as a medicalized condition

The last theme identified in this analysis was describing disability identity as a medicalized condition. While participants did not necessarily identify themselves as disabled, they tended to

discuss their disability identities using medicalized and biological terms. Skywalker consistently referred to the biological aspects of his hearing loss throughout his interview and also applied this same perspective to his Asperger's Syndrome:

I look at it more from a biological, medical standpoint. I do understand that for some disabilities, such as Asperger's, there's a community where they have their own lingo or jargon, and their own way of saying things as well. Like [people with] Asperger's [Syndrome] sometimes refer to each other as Aspies.

In this quote, Skywalker also acknowledged more community-based associations that individuals who identify as having Asperger's Syndrome make with one another. Notably, Skywalker refers to his disability identity as Asperger's Syndrome, which is now classified with Autism Spectrum Disorder (ASD), thus further reflecting the fluid evolving nature of the ways disability identity is communicated. Bubba also focused on the medical aspects of his Lyme Disease diagnosis, but his disability identity hinged on identifying changes in his academic performance and stamina to get through day-to-day tasks as a college student. These differences were further articulated when Bubba described experiences of severe fatigue and lethargy during a civil engineering conference – an environment that typically fueled his energy and passion for the field. Because of this, he positioned his diagnosis as validating:

So, I mean it didn't mean a whole lot when I was diagnosed with it. Honestly, it was more relieving than anything because I had no idea what was wrong with me, I just knew there was something wrong and I didn't feel myself. So, once I got diagnosed, that was relieving because then I knew there was a cure. I know that there was a way to go back to normal, even if it would take time.

Bubba's use of terms such as 'wrong' and 'cure' exhibit the medicalized perspectives through which he positions and defines his disability identity. Such medicalized perspectives also influenced how we, as a research team, recruited students to gain their perspectives. While Deena did not consider herself to be disabled, she tended to focus her disability identity on the named condition of ADHD. This focus is demonstrated as Deena describes her thought process for deciding whether or not she qualified for participation in this study:

Because I remember just seeing [the recruitment email], and I was like, 'Oh, students with disabilities.' I was like, 'Oh, well, I can do that because I have [ADHD]. Because I feel like I don't really see a lot of things about studies and being a part of [students with disabilities], so I felt that if this was something that I could be a part of, it would be interesting to be a part of something about students with disabilities and just civil engineering, because it just is two things together.

Deena did not necessarily consider herself to be disabled, but when she saw that ADHD was listed as a qualifying condition for participating in the study, she decided to volunteer. Her reflection also highlights the salience of her professional identity as a student in a civil

engineering program. Belonging to both groups (i.e., individuals with ADHD and civil engineering) was the ultimate deciding factor for Deena to self-select into the study.

Discussion and Implications

The themes identified in this work demonstrate the complex ways that individuals draw from medical, social, and social-relational perspectives to define disability identity in their own contexts. While the medical model of disability is criticized for its emphasis on impairment and deficit to an assumed normality [1], it also serves as a foundation on which our participants discuss and describe their disability; they often used specific labels for conditions and articulated disability through experienced symptoms. These findings cohere with conversations in disability studies on shifting from a focus on impairment and curing to thinking about disability as a category that provides meaning-making of experiences and community [24]. As a result, this work highlights several areas for future work and implications for civil engineering and engineering, broadly.

As part of our larger grounded theory study [6, 13, 14], this analysis enabled us to identify the abstract ways that our participants conceptualized and defined disability identity as they progressed through their civil engineering programs and into their careers. In future work, we will use the definitions and categories identified in this analysis to finalize and articulate the relationships between disability and civil engineering identity in the final iteration of our grounded theory model.

Within Civil Engineering, specifically, this work underscores the need for the recent expansion of the American Society of Civil Engineers (ASCE) Civil Engineering Body of Knowledge [25] that includes affective learning outcomes and centers the value of human experience. Aligned with calls from the Civil Engineering profession, it is imperative that our value of the human experience results in social structures that promote the participation and inclusion of students and colleagues with disabilities in engineering. For civil engineering faculty, instructors, and administrators, it is imperative that we employ educational strategies that center accessibility and inclusion as necessary and vital components, rather than afterthoughts or add-ons, to civil engineering design practice. Such strategies include consistently revisiting and referring to the expanded ASCE BOK and implementing concepts of Universal Design (UD, [26]) in core civil engineering courses. Moreover, academia (i.e., faculty and university-sponsored career centers) need to intentionally work with industry to remove barriers that limit student access to the wide variety of career pathways available in the civil engineering field. Not all positions require that students spend endless hours behind a desk working calculations, nor do they all require that students roll heavy wheelbarrows of concrete across a construction site. Providing support to assist students in choosing the best career pathway can significantly bolster the presence of civil engineers with disabilities in industry.

While the participants in this study were enrolled in civil engineering programs, our findings likely also have significant implications for engineering education broadly because many of our participants did not localize their experiences to civil engineering specifically or exclusively.

Instead, the experiences and identity formation processes described by our participants occur within a larger culture of engineering that seeks to erase difference [27] and that operates on implicit assumptions of meritocracy – that anyone “capable” of succeeding in an engineering program will, and will succeed ‘on their own merits’ (e.g., [28]). Therefore, we must instill a larger culture change in engineering education that recognizes that systems of education, as we currently know, structure, and implement them, were not created with students with disabilities in mind. In some instances, these institutions were created to intentionally exclude and discourage students with disabilities from pursuing degrees in higher education, especially in engineering and other STEM fields [5].

Collectively, we must create a culture that places less emphasis on medicalized labels and individual accommodation and more on creating adaptive, flexible environments, policies, and systems that are more widely accessible to all. Such principles are embedded within the Universal Design for Learning (UDL; [29, 30]) framework that guides educators to create instructional and assessment approaches that can be easily adapted to fit learners’ diverse needs. Adopting this approach also lessens faculty reliance on university-sponsored Disability Resource Centers, which tend to focus on compliance and preventing disability discrimination lawsuits rather than on supporting the social and identity formation of college students with disabilities. [31, 32, 33] Lastly, we can showcase the work and stories of disabled students, faculty, and industry professionals to dismantle definitions and cultures that position the disabled community as a group for engineers to ‘help’ and ‘fix’ rather than as engineers, themselves [34]. By employing these strategies, we can individually embody the outcomes necessary for the collective cultural de-stigmatization of disability in engineering, and we must lead and encourage our colleagues and students to do the same.

Conclusion

The majority of our participants did not identify as disabled, yet they defined and described their disabilities through lived experience and medicalized terms, and their experiences point to critical areas of needed transformation in the culture of engineering education. Overall, this work contributes to conversations that emphasize the diverse and fluid ways individuals with disabilities define and conceptualize disability in engineering and in our society [1, 6]. However, our first identified theme, describing disability identity as a characteristic that ‘sets you apart’, may reflect deeper misconceptions that typically associate disability with helplessness, vulnerability, and poor quality of life and stereotypes and position it as an obstacle to be overcome [3, 35, 36]. While this work amplifies the voices of our participants to shed light on the various ways disability can be experienced and interpreted, it also highlights the need to critically challenge inherent ableist norms that shape our social, educational, bureaucratic, and physical systems. By redefining and reconceptualizing disability as difference, rather than a deficit, we can more intentionally create inclusive environments that destigmatize disability position participation in our academic and professional communities as a right rather than a privilege.

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