

"I'm looking at you, you're a perfectly good person ...": Describing Non-Apparent Disability in Engineering

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Introduction

In recent years, studies in engineering education have begun to intentionally integrate disability into discussions of diversity, inclusion, and equity. To broaden and advocate for the participation of this group in engineering, researchers identify a variety of factors that have kept people with disabilities at the margins of the field. Such factors include the underrepresentation of disabled individuals within research and industry [1]; systemic and personal barriers [2], [3], and sociocultural expectations within and beyond engineering education-related contexts [4]. These findings provide a foundational understanding of the external and environmental influences that can shape how students with disabilities experience higher education, develop a sense of belonging, and ultimately form professional identities as engineers [4]–[7].

Prior work examining the intersections of disability identity and professional identity is slowly emerging [1], [4], [5], [8], with few studies examining the ways students conceptualize, define, and interpret disability as a dimension of identity during their undergraduate engineering experience. This lack of research poses problems for recruitment, retention, and inclusion, particularly as existing studies have shown that the ways in which students perceive and define themselves in relation to their college major is crucial for the development of a professional engineering identity [4], [7]. Moreover, the term “disability” is broad and often misunderstood due to the various ways it is defined and described across disability models. For example, the medical model, prominent in national agencies such as the National Institutes of Health and the Department of Justice, defines disability in terms of a treatable condition. In contrast, the social and social-relational models of disability, prominent in scholarly fields and advocacy groups, define disability as a social construction that is generated by interactions with systems, structures, and societal norms that are generated by and for people without disabilities. These definitions implicate a variety of individuals and a wide range of conditions, social attitudes, and experiences.

As part of a larger grounded theory exploration of professional identity formation in undergraduate civil engineering students with disabilities [4], the purpose of the present study is twofold. First, we seek to gain a baseline understanding of students’ conceptualizations of non-apparent disabilities. Second, we seek to explore the ways disability models capture or emerge from students’ descriptions of their experiences. To guide this inquiry, we ask the following question: How do students describe non-apparent disabilities? To answer this research question, we conducted an exploratory analysis of semi-structured interviews of four undergraduate civil engineering students who have disclosed a non-apparent disability to the research team. In the following sections, we discuss and provide rationale for scoping the present study to participants with non-apparent disabilities, the sensitizing concepts framing this work, and describe overarching themes as articulated through participant experience. We conclude with implications for researchers and educators as well as areas for future work.

The Significance of Non-Apparent Disabilities and Identity

Often referred to as invisible or hidden disabilities [9], [10], we intentionally describe non-apparent disability as a type of disability that is not immediately observed or experienced by another individual. These disabilities include learning disabilities, mental health disabilities, and certain types of developmental or cognitive disabilities [11]. Current statistics suggest that approximately 19% of college students identify as individuals with disabilities, with a majority of these individuals disclosing a non-apparent disability [12]. Prior work has identified that college students with non-apparent disabilities are more likely to drop-out of school and academically underperform than their peers without non-apparent disabilities [11]. In part, this likelihood stems from the fact that for many students with non-apparent disabilities, disclosure often includes an assessment process in which a student considers the stability of their non-apparent disability, implications for not receiving an accommodation, and the stigma that may be attached to them in light of their disclosure [11], [13].

This necessary assessment process inherent to disclosure for many students varies across both individual faculty members and institutional contexts. In their examination of faculty willingness to provide quality disability services, Zhang and colleagues [14] found that faculty members' personal beliefs significantly influenced the extent to which they provided reasonable accommodations to students. Rao and Gartin [15] found that perceptions of accommodations varied by faculty ranks, with part-time and non-tenure track faculty demonstrating significantly better attitudes toward providing accommodations for students than their full-time and tenure-track peers. At a university level, Mayat and Amosun [16] found that despite faculty willingness to admit and accommodate students with disabilities at their university, these same faculty lacked the knowledge and support necessary to provide accommodations to students. In contrast, Groen-McCall and colleagues [13] identified hostile environments in which accommodations were perceived by faculty as a form of "extra help" or an attempt to "cheat the system".

From a social identity perspective [17], [18], non-apparent disabilities also hold significant implications for identification within the disability community because they cannot be easily observed or experienced by others. That is, while a student may position themselves as disabled, they may not be positioned as such by their peers or faculty. This interpretive perspective surrounding non-apparent disabilities may be traced to broader culturally established colloquialisms and societal expectations that shape the ways individuals with disabilities navigate and are perceived to navigate political, social, and physical institutions and systems. In popular conceptions, people with disabilities are often conceptualized based on visual indicators that signify or enact disability. For example, blindness is often conceptualized as complete darkness and signaled through the use of assistive aids and technologies (e.g., canes, guide dogs, screen readers, etc.). However, less than ten percent of individuals who identify as blind possess no light perception whatsoever [19]. As such, many blind or visually-impaired individuals may choose not to utilize assistive tools that would otherwise indicate their disability. These absent or contradictory visible indicators often create social challenges. For example, individuals with learning disabilities who perform well in school may be questioned regarding their need for accommodations because learning disabilities are culturally imagined to result in poor academic performance [13]. From this perspective, individuals with non-apparent disabilities often contradict popular expectations of what disability is and who disabled individuals are [7].

In this paper, we contribute to conversations surrounding approaches to defining disability. As such, we turn to study participants, themselves, to further examine the ways in which they conceptualize disability from their own lived experiences and within their own contexts. Drawing from models of disability, such as medical, social, and social-relational, we seek to reveal the paradigmatic underpinnings that ultimately shape how students position disability as they form disability and engineering identities during their undergraduate careers. In addition to answering the research question, however, we also seek to increase awareness across the engineering education community regarding students' experiences with non-apparent disabilities and further bolster scholarly initiatives that more intentionally include individuals with disabilities in higher education.

Sensitizing Frameworks

To help frame our exploration, we draw from three existing constructs in Disability Studies: 1) the medical model of disability, 2) the social model of disability, and 3) the social-relational model of disability. First, medical models of disability position physical, cognitive, and developmental difference as a “sickness” or “condition” that must be “treated” [20], [21]. From this perspective, disability is perceived as an impairment that must be accommodated so that individuals can obtain a dominantly-accepted sense of normality. An example of medical models within education include accommodations procedures in which students must obtain an official diagnosis in order to access tools necessary for academic success. Second, social models of disability position disability as a dynamic and fluid identity that consists of a variety of physical, cognitive, or developmental differences [22]. Dissenting from assumptions of normality and the focus on individual bodily conditions (hallmarks of the medical model), the social model focuses on the political and social structures that inherently create or construct disability [22]. For example, within education, employing universal design to make materials and tools accessible to all students within a given course positions disability as a social construct that can be mediated by adapting one's surroundings. That is, the environment, not the individual, is altered to meet educational needs. In these instances, students are not required to request accommodations and may bypass medical diagnoses. Lastly, the social-relational model conceptualizes disability as generated through social relationships that are controlled and constrained by social structures and actions [23]. For example, in the institution of US education, which is socially positioned as meritocratic in nature, individuals with disabilities may experience social stigma from individuals who view accommodations requests as “extra” or unnecessary help. From this perspective, the social-relational model combines aspects of the medical model (i.e., disability as condition) with those of the social model (i.e., disability as generated by surroundings) to capture the lived experiences of individuals with disabilities as they interact with the world around them. A summary of these models is presented in Table 1.

Table 1: Summary of Models of Disability

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 a baseline understanding of the ways students describe their non-apparent disabilities, we chose to implement an inductive qualitative approach heavily inspired by grounded theory and initiated using the sensitizing concepts presented in the previous section. Data collection was conducted by purposively sampling interview transcripts from four students who identified themselves as having a non-apparent disability and are currently enrolled in an ongoing, nationwide grounded theory exploration of the professional identity formation of undergraduate civil engineering students with disabilities (for more information on this study, including recruitment and data collection, see [4], [7]). Due to the exploratory nature of the present study, four participants (17% of participants with non-apparent disabilities) who disclosed a non-apparent disability and could mostly clearly define and articulate their experiences were purposely selected for analysis. This allowed the research team to pilot a new analysis technique that integrates frameworks from the field of Disability Studies with the experiences of engineering students. For this initial analysis, we selected a purposeful sample of four participants meeting the following criteria: 1) identifying as having a non-apparent disability, and 2) providing rich descriptions of their experiences as related to their disability. Twenty-two participants met these criteria, and of those, we selected the four with the most concrete and extensive descriptions to allow us to develop a richer and more robust codebook, presented here, that can be used in future work. Interviews were semi-structured, lasted approximately 60-90 minutes, and captured participants' descriptions of and experiences of disability. We chose to scope our inquiry to students with non-apparent disabilities because their interviews highlighted differential experiences when engaging in academic processes such as requesting accommodations and the stigma associated with having a disability that cannot be easily identified by others. Study participants consisted of students currently enrolled in undergraduate civil engineering programs, students who were initially enrolled in undergraduate civil engineering programs and transferred to another major, and students who have recently graduated from a civil engineering program within the past year. All study procedures were approved by the Virginia Tech Institutional Review Board.

Data analysis followed emergent, inductive approaches, as outlined in grounded theory coding procedures by Charmaz [24] and conducted by the first author. Analysis was conducted using three phases and is shown in Figure 1. In phase 1, a general review of participant transcripts was conducted to familiarize the first author with the data and identify resonating features and themes in participant transcripts. In phase 2, a codebook was developed drawing from sensitizing concepts of medical, social, and social-relational models of disability. Codes were identified as instances in which participants explained, described, or experienced dimensions of disability (e.g., through diagnosis, interactions with their environment, interactions with others, etc.) throughout their lived experience. These instances are further described in the next section. Code names and categories were created to account for participant context and were iteratively adjusted as analysis of transcripts continued. During phase 3, the codebook was applied across transcripts to ensure that all relevant instances were captured. Throughout the coding process, members of the research team iteratively met to ensure quality and agreement of the emerging codebook and highlight the various ways each disability model manifested within participant interviews.

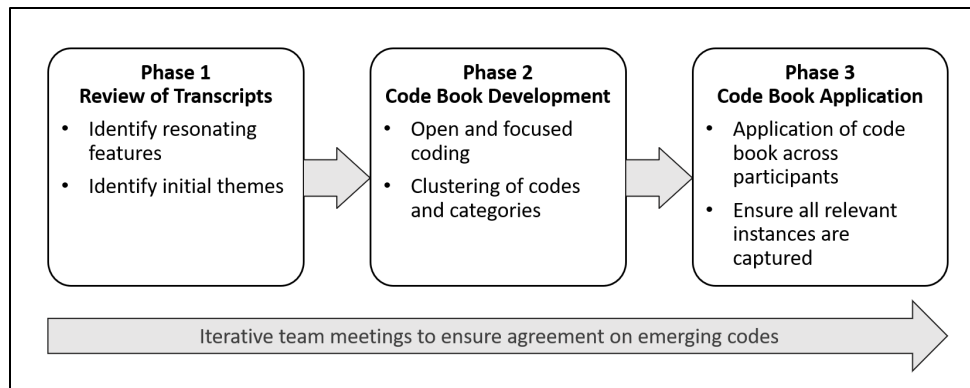


Figure 1: Summary of analysis process

Results and Discussion

Our discussion begins with the exploratory analysis of four sampled research participants who identify as having non-apparent disabilities. We begin with Bubba, whose experiences as a student with a non-apparent disability was most often described from a medical model perspective. In contrast, Alexa and Sammie, the medical model emerged somewhat less frequently, while the social and social-relational models were more common. Finally, Edith's discussions of her experiences ranged relatively equally across all three models. In the following sections, we review patterns identified within the context of each participant and conclude with a summary of patterns across participants.

Bubba

Bubba is a civil engineering student who is living with Lyme disease and was only recently diagnosed during his freshman year of college following a variety of symptoms, including excessive lethargy, skin rashes, and some cognitive impairment (i.e., "brain fog"). Along with these explicit symptoms of Lyme disease, Bubba also described an onset of anxiety related to managing these new medical symptoms as well as facing his expectations as a student in a civil engineering program.

The analysis of Bubba's interview yielded 92 codes related to his experiences through the medical (53%), social (21%), and social-relational (26%) models. This analysis suggests that Bubba's experience of living with a non-apparent disability presented most prominently through the medical model, as suggested by the following explanation:

I have something that's impairing me, from being able to perform at a normal rate. So, yeah, I guess I would consider myself disabled, just to a much lesser extent than a lot of other people are, which is I guess why I don't tell a lot of people about it. If it was something that was noticeable, then like right off the bat, then I probably would talk about it more often than I do, but typically I try not to just so I don't think about it all that much and I can also go back to normal at some point. I could be perfectly fine again in time, I'm sure, but it's hard to say because if you talk to any doctor, they have such different opinions on it and everything.

Bubba's use of terms such as "impairment" and "normal" align closely with the medical model by framing Lyme disease as a condition that hinders "normal" functioning. The prominence of this medical model may be due to the timing of Bubba's diagnosis, which occurred only months before this interview, and thus the development of his disability identity was still relatively new. Throughout his interview, Bubba described a supportive campus culture, which may have allowed him to focus more on symptom management (i.e., a medicalized model), thus situating experiences such as accommodations requests (i.e., social model) and faculty interactions (i.e., a social-relational perspective) as less prevalent in defining his non-apparent disability. However, future work will need to be conducted to explore this observation.

Alexa

Alexa, like most participants in the larger study, reported a long and arduous path toward diagnosis that began during adolescence. After experiencing ongoing and worsening symptoms such as chronic pain in her back and joints, along with a depressed mood and lack of motivation during high school, Alexa obtained a diagnosis for postural orthostatic tachycardia syndrome (POTS), which she described as "validating". POTS, which is best understood as poor blood flow circulation throughout the body, resulted in the type of intense chronic pain that she experienced. After this primary diagnosis, Alexa was further diagnosed with fibromyalgia, median arcuate ligament syndrome (MALS), and depression in a process that was still ongoing at the time of the interview during Alexa's senior year of college.

Analysis of Alexa's interview yielded 64 coded segments, with the social (39%) and social-relational models (33%) somewhat more common than the medical model (28%). She tended to describe her non-apparent disability through social experiences as an engineering student. Specifically, Alexa described how she manages her disability within her social environment through the use of accommodations:

When I think of being disabled I think of someone who needs help. Which could be any aspect. Which, I don't know if that's politically correct or anything. So I guess in how that relates to me, I do need help, and the way that I think of that is, because I have my specific disability accommodations, that's the help in my mind. So I guess if I could sum it up I'd say, I am disabled because I need help, especially with my school work, and I get that help, so that's how it relates to my studies in construction engineering.

As she explains, Alexa's disability identity was heavily influenced by her social environment, evident in this link between needing and receiving accommodations. She further described a lack of faculty knowledge in providing support in upper level courses of her degree program:

So because [so few students with disabilities persist in engineering], these professors that only teach the high-level engineering class, they honestly just might not know what to do with us. "I'm not asking you to bend over backwards for me," it's really not that difficult to send out [an] email asking for someone to get a note taker, but to [faculty] it's like, "What in the world is that?" [...] I guess

the note taker [accommodation] is probably more, it's more common to get, not backlash, but uncertainty from the professors from that.

Drawing from these experiences, we surmise that Alexa's tendency to define non-apparent disability from social and social-relational perspectives may be indicative of the daily tasks she experienced at the time of the interview, which included requesting accommodations to complete her final courses as a senior on the cusp of graduation.

Sammie

Sammie was diagnosed with attention-deficit hyperactivity disorder (ADHD) during high school. ADHD is most commonly identified as a cognitive difference that impacts an individual's focus and self-control. Sammie described first noticing difficulties in maintaining focus in class and when working on assignments. Sammie, who struggled with others (i.e., teachers, family, and peers) perceptions of her disengagement, practiced self-advocacy to achieve a diagnosis as a minor. After going through numerous medical tests and receiving a diagnosis, Sammie described relying on "self-deprecating" humor to relate to her peers who were "neurotypical," highlighting the social-relational influences on her conceptions of non-apparent disability.

Analysis of her interview yielded 60 coded segments, and like Alexa, her descriptions of living with a non-apparent disability emphasized the social-relational (42%) and social (35%) models more prominently than the medical model (25%). Sammie often highlights the interplay between the social and social-relational models of disability through her experience as an engineering student with a non-apparent disability as follows:

But when you have a disability, you can't just solve it. And also, I think that engineers, we have this idea, we have this concept of we're solving problems. That's all really, most of what engineers do is we solve problems. And it's like, sometimes I feel like it's a problem that I can't solve, so I just don't talk about it. With my friends, I pretend that it doesn't exist, because it's something that I can't deal with or correct or solve.

Sammie's interview explicitly highlights the connection between her engineering student identity and her disability identity as experienced in relation to her friends and classmates, as well as the overall culture of engineering. She discusses her cognitive experience of feeling stuck in trying to solve her disability the way she would an engineering problem, and that feeling creates barriers in practicing vulnerability through self-disclosure within her relationships.

Edith

Edith was diagnosed with post-traumatic stress disorder (PTSD) and depression during their freshman year of college. Like many students, Edith described an initial interest to major in civil engineering grounded in family influences (e.g., working on the family farmhouse with their dad), academic interests (e.g., science and math), and access to a stable income and independent lifestyle upon graduation. Prior to college, Edith was aware of the masculine culture of

engineering, and when asked if that was something that influenced their decision to pursue civil engineering, they replied:

I think I was a pretty fearless person, and I wasn't concerned with the gender binary. I had stereotypically masculine hobbies. I have short hair. Maybe not today, but I really just wear jeans and a t-shirt. Yeah. Looking back, I think that maybe I should've considered that a little more. I find the engineering center to be a pretty hostile place.

Upon reflection of this decision, Edith indicates a sense of regret (i.e., "...maybe I should've considered that a little more."), describing her institution's engineering center as "a hostile place". Analysis of Edith's interview yielded 47 codes distributed almost equally across the medical (32%), social (34%), and social-relational (34%) models, reflecting a time where Edith was simultaneously experiencing diagnosis procedures and the dominant engineering culture at their university. The following comment illustrates the interweaving of these models:

I really, genuinely feel unable to do things that I used to be able to do, or maybe I can do them but it's very difficult. Another symptom I experience is inability to focus. I don't know if there's really a term, but my brain is just dulled. In engineering, these complex math problems where you have to focus for a long time and be really aware, I'm not able to do those. I used to have an internship with the school. I had to quit that. It's just really hard to do anything. Get out of bed, talk to people, ask for help, even... and homework is really difficult. Yeah. That's a hard thing to admit to yourself.

Here we see how Edith's experience with a non-apparent disability impacts their cognitive and social functioning, which they frame as impairments (i.e., they are unable to do things they used to do). Those symptoms then impact their ability to complete the social requirements of their environment, such as required coursework and the ability to engage with peers socially.

Patterns Across Participants

In addition to highlighting the ways in which the various models of disability manifested themselves in the experiences of these engineering students, our analysis also highlighted several patterns that help answer our overarching research question. With respect to describing disability, all participants examined in this analysis described disability in language related to all three disability models (i.e., medical model, social model, social-relational model). These descriptions emerged from various aspects of the participants' lives as they navigated diagnostic processes, social institutions, academic culture, and social interactions with peers and faculty. Notably, these models often overlapped, or co-occurred, throughout participant transcripts, revealing a complex relationship in the ways that participants conceptualized disability across their experiences. Further work will need to be conducted to examine when, why, and how these models interact to inform individuals' descriptions of non-apparent disability.

Future Work

Overall, the findings from this study reveal more questions than they answer. In particular, three significant observations emerged related to participants' descriptions of non-apparent disability that warrant further investigation. First, participants typically described their non-apparent disability through comparisons of their peers perceived as having or assumed to have a disability. Currently coded as "subjective severity," these comments reflect the ways that participants assessed the extent to which their disability influenced their experiences as undergraduate engineering students and their ability to adhere to expectations and norms of higher education. Future work in this area will include an in-depth examination of these comparative processes and influences on students' overall identification with disability and the engineering field.

A second observation that warrants future work is the stigma that is often associated with disability. Stigma has been defined as "the disapproval and disadvantages that [are attached] to people who are seen as different" [25]. However, the stigma attached to individuals with a non-apparent disability seems to differ from that attached to individuals with apparent disabilities. The majority of participants in this study disclosed experiences of having to practice forms of self-advocacy in order to be believed when they did decide to disclose their non-apparent disability to receive university accommodations. Alexa describes her experience of this stigma when she stated, "They don't believe it, they don't think you're being serious. 'Why does someone have to take notes for you? I'm looking at you, you're a perfectly good person ...' That's a whole other issue I guess, where we go into the invisible disabilities aspect of it." This pattern of a lack of believability due to invisibility perpetuates marginalization of this population. While faculty and universities are becoming more supportive of students with disabilities [16], [26], progress is slow and more work needs to be done to intentionally include individuals with non-apparent disabilities. In this study, participants described the majority of their experiences when requesting accommodations through faculty to be largely negative in context. These findings again highlight the complexities in the intersectionality of an individual's student identity, their disability identity, and the ways they are allowed to navigate the academic context.

Lastly, participants defined and described disability that reflected conflict with aspects of their professional and personal identities. Sammie, for example, considers her ADHD to be a disability because it is something that cannot be "solved" and cannot be reconciled with her engineering identity as a problem-solver. Bubba, who received his diagnosis only months prior to the interview, identified his disability as "an impairment from being able to perform at a normal rate" and focused much of his discussion on continued symptom management and treatment. This medical perspective may be due to the timing of his diagnosis, particularly as he continues to make meaning of this newly acquired identity, and we will continue to explore this development in future interviews. These experiences highlight the complex intersections of disability models, identity, and their contextual influences participants experience as they navigate their lives. Further work will investigate this nuance and unpack these interactions.

Conclusions and Implications

In this paper, we presented an exploratory analysis of four engineering students' descriptions of their experiences with non-apparent disabilities, highlighting the ways that each of the three

primary models emerged in their discussions. For some participants, such as Bubba, disability is primarily medicalized whereas Alexa and Sammie primarily describe disability from the social and social-relational models of disability. Edith, in contrast, tends to draw from all three models to describe her experience with disability. These variations may be due to personal characteristics of each participant (e.g., family background, time of diagnosis, academic experiences), the cultural contexts of their universities or programs, and/or the social and cultural constructions and (lack of) affordances associated with disabilities themselves. More work is needed to better understand the factors that contribute to the ways non-apparent disabilities are experienced and communicated.

Findings from this work will be used to further explore the professional identity formation of undergraduate civil engineering students with disabilities. For practitioners, these findings highlight a number of key implications for students with non-apparent disabilities in the classroom. Because non-apparent disabilities are not easily experienced or observed in our students, it is important that we preemptively employ such practices as Universal Design for Learning (UDL) [27] that promotes flexible and adaptive course and curricular structures that move beyond individual accommodation and toward universal accessibility. For higher education, broadly, this work reinforces the complex and diverse nature of disability experience and identity, particularly as it relates to accommodations and accessibility within the classroom and expand the inclusiveness of our programs and institutions.

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