Diminishing the Data Divide: Interrogating the State of Disability Data Collection and Reporting

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Abstract
This research paper explored the availability of data for disabled students in postsecondary engineering programs in the U.S (using [1]–[9]). The paper reviewed a variety of sources for the reporting of disability-related demographic information for these programs. Examples of these sources include funder reports (e.g., NSF Diversity and STEM, ASEE By the Numbers) and educational data repositories (e.g., NCSES, IES). We investigated first, if disability is at all included in the reporting of demographic information. If included, we looked at the criteria to count someone as disabled. Implications of our findings include (1) considerations for using existing data sources and (2) recommendations for improving the capture of demographic and identity-related information to include disability and its related nuances. The findings from this study underscore the need for the comprehensive inclusion of disability-related demographic data in postsecondary engineering programs, while highlighting existing challenges and opportunities for improvement in data collection methods.

Keywords
Students with disabilities, higher education, action research, diversity concerns, content analysis

Introduction

Disability as a concept is a complex, polymorphous descriptor often used to delineate the experiences of individuals' interactions with a medical condition and resulting social and/or environmental factors [10]. Disabled as an identity is equally as complex and nuanced, circumscribed by a diverse group of individuals across genders, races, ethnicities, and socio-economic backgrounds. The disabled community represents a substantive portion of the world's population, comprising around 1.6 billion people [10]. In higher education, around one in five undergraduates identify as disabled [11]. Yet, in engineering such substantive data is almost entirely unavailable. The National Science Foundation (NSF)'s 2023 Diversity and STEM: Women, Minorities, and Persons with Disabilities report states, "compared with data for other groups, data on postsecondary degrees earned by persons with disabilities are limited" [1] and as such, provides no data on disabled engineering undergraduate students and diminutive data on disabled engineering doctoral students. Whether it be funding, available statistics, access, or support, the lack of care toward disabled students in engineering is apparent and intentional [12]–[16].

This paper explores the availability of data for disabled students in postsecondary engineering programs in the US (using [1]–[9]). We reviewed nine annual funder reports and educational data repositories that report student demographic-related information within engineering and higher education more broadly. Within these data sources, we examined the inclusion of disability and if included, the extent of information provided. Through this study, we explore the following research questions (RQs):

RQ1: What is the state of disability-related data reporting across STEM higher education data sources?
RQ2: What is the breadth of information provided in these data sources, as it relates to disability data?

Background

Use of Language

There are many language options when it comes to talking about disabled people. Person-first language highlights someone's personhood before mentioning their disability (e.g., "person with disabilities"). Identity-first language mentions the disability before the person (e.g., "disabled person") [17]. All authors identify as disabled and use both identity-first and person-first language in their writing. However, it is also important to note that we both prefer identity-first language for ourselves. We believe that using identity-first language is important to bring visibility to the disability as an identity, build community, and seek needed resources. We ask that non-disabled people mirror and respect the identity labeling preferences of the disabled person or group that they are interacting with and/or communicating about. In this paper, we use person- and identity-first language to mirror the different language preferences of those within the disabled community.

Disabled Students in Engineering Education

Engineering as a field holds the belief that "bodily normalcy" defines intelligence, self-control, and motivation [18]. Such ableist beliefs encountered by disabled students in engineering spaces transcend into doubts about their engineering skills and abilities and their potential to be professional engineers [12], [19]. Subsequently, students with disabilities have lower college aspirations and feel discouraged about taking engineering-related courses when they leave high school, due partially to lack of support from teachers and guidance staff related to postsecondary STEM opportunities for disabled students. Disabled students who do choose the postsecondary engineering pathway are less likely to request accommodations than students with disabilities in other disciplines, chiefly due to the stigma around accommodations and disability in engineering [20]. This stigma manifests in many ways, such as the view that accommodations are a "[way] to cheat the system" [16], [21]. Engineering's definitions the "ideal" students has an overabundance of further implications for disabled students, like shame around disabled identities [12], the emotional labor involved in accommodations request processes [22], and deterring students from pursuing engineering altogether [23].

In spite of all this, disability is rarely mentioned in conversations about broadening participation or educational justice in higher education or engineering [18], [24], [25]. Few studies have explored disability in the higher education context, let alone the engineering context. This study builds on past research on disabled student experiences in engineering [12], [26] to initiate the discussion on inequitable barriers for students with disabilities in postsecondary engineering education.

DisCrit

DisCrit is a sibling of Critical Race Theory [27], which uses an intersectional approach to inform the work we draw from, the questions we ask, and how we navigate such inquiries. Drawing from Critical Race Theory and Disability Studies, DisCrit "recognizes that race and disability are mutually constitutive social constructions with material realities" [23, p.42]. It emphasizes how perceptions of race often influence the perception and evaluation of one's abilities in cognition, learning, and behavior [29]. As a result, DisCrit offers a valuable theoretical framework for examining relationships and tensions because it recognizes the interdependence of racism and ableism, which makes people holding multiple marginalized identities increasingly vulnerable to interpersonal and state violence [28].

In our work, DisCrit frames what is known and understood about disabled students in engineering education, as well as identifies areas for further research. More specifically, DisCrit acts as a guide between (1) what is known on the topic of disability, disabled students, and higher education, (2) identifying the gaps in such research, (3) scoping how to analyze the data (i.e., systematic), and (4) the intended outcomes of our research.

Author Positionalities

The first author identifies as disabled and white and is a Ph.D. student in Purdue University's Engineering Education program. They developed chronic migraines during their BS in Electrical Engineering at Purdue and struggled to get their accommodations fulfilled in engineering courses. They spent five years working in industry between undergrad and grad school. They got diagnosed with ADHD in 2021, right before starting their Ph.D. program. They use their experience navigating accommodations in undergraduate and graduate education, as well as working in industry, to inform their research.

The second author identifies as a disabled white woman and is a Ph.D. candidate in Arizona State University's Engineering Education Systems and Design program. Her research is largely informed by her own experiences with academic ableism throughout all stages of education. As someone who was diagnosed and received disability accommodations from a relatively young age, she developed an early understanding of how to navigate educational systems while being disabled. These experiences have made her hyper-aware of the pervasiveness of ableism in U.S. educational contexts and how ableism may appear differently throughout each stage of education (i.e., pre-college, undergraduate, and graduate), all of which has given her an increased understanding of the complexities that define the disabled experience and the community of care needed to work with disabled students. The goal within her current work and all of her future work is to build community, while empowering, uplifting, and advocating for disabled voices.

Methods

Research Design

To better understand the broader context of disability data representation in engineering higher education, we conducted a content analysis of STEM research funder reports and educational data repositories. There is a tight link between the representation of data and equity [30]. The availability of data are crucial to identifying disparities, making funding allocation decisions, and promoting change [31]. Large STEM funder reports and educational data repositories often serve as the primary source for determining the representation of different identities within engineering. As such, the collection of demographic information related to disability as an identity becomes unequivocally important.

Data Collection

Data collection was scoped to the reporting of disability-related demographic data in higher education settings. To further guide our data collection process, we utilized the research question and goals of this study to outline four main inclusion criteria for finding relevant data sources:

1. The data source must include postsecondary education data
2. The data source must capture U.S.-specific data
3. The reporting organization must be a STEM-related funder or data repository
4. The reporting organization must be a national funder or data repository

This study presents an analysis of reported disability-related demographic data from nine sources, all of which were either large STEM education funder reports or educational data repositories. These nine sources were selected to obtain a range of report types (funder report versus data repository), higher education contexts (engineering or STEM-specific versus higher education), and reporting organizations (government versus non-profit organization). Additional information about the data reports and the reporting organizations can be found in Table 1.

Table 1
Data Source Classifications and Related-Information

Name of Data Source	Reporting organization	Source type	Higher education context	Entity type of reporting organization
Diversity and STEM: Women, minorities, and persons with disabilities (2023) [1]	National Science Foundation	Report	STEM-specific	Government
Digest of education statistics (2021) [2]	National Center for Education Statistics (NCES)	Data Repository	Higher education	Government
Report on the condition of education (2023) [3]	NCES	Report	Higher education	Government
Education across america (2023) [4]	NCES	Report	Higher education	Government
Making visible the invisible, 2023 Committee on Equal Opportunities in Science and Engineering (CEOSE) Report (2021-2022) [5]	National Science Foundation (NSF)	Report	STEM-specific	Government
Engineering and engineering technology by the numbers (2023) [6]	American Society of Engineering Education (ASEE)	Report	STEM-specific	Non-Profit
Annual report for The Spencer Foundation (2021)[7]	The Spencer Foundation	Report	Higher education	Non-Profit
Higher education in science and engineering (2023) [8]	NSF	Report	STEM-specific	Government
The state of U.S. science and engineering (2022) [9]	NSF	Report	STEM-specific	Government

Data Analysis
First, we investigated if disability was at all included in the reporting of demographic information. If included, we looked at the language and breadth of information provided to report disability-related demographic information. The research team created evaluative criteria to ensure scoring

consistency across data sources (Figure 1). Scorers rated each criterion yes, somewhat, no, or unclear based on the predetermined evaluative criteria. A criterion was rated as "somewhat" if the data source included partial information. For example, if a definition of disability was listed in the Appendix of a report but not mentioned in the actual report. A criterion was rated as "unclear" if the data source did not discuss the specifics of a measure. For example, if a report did not describe the data's origin and/or collection methods we could not deduce if the U.S. Department of Health and Human Services' (HHS) "six minimum questions to ask about disability" [32] were asked during data collection.

Members of the research team independently reviewed each data source. After the independent reviews were completed, the team met together to discuss initial findings and obtain consensus on each criterion's rating. The reviewers' conclusions were guided by iterative and critical reflection at each stage of the analysis process.

Figure 1

Evaluative Criteria for the Reporting of Disability-Related Demographic Information

1. Is disability included as a demographic characteristic? (Yes, no)
    a. Does the disability data include postsecondary? (Yes, no, unclear)
    b. If not, what category does the disability data fall in?
2. What language does the data report use when talking about disability? (Person-first, Identity-first, Disability as a functional limitation)
3. Is a definition given for "disability" or information provided on how the data report conceptualized "disability"? (Yes, somewhat, no, unclear)
4. To what extent do the data reports disaggregate disability-related demographic data?
    a. Is disability lumped together as one demographic characteristic? (Yes, no, unclear)
    b. Are disabilities divided into categories? (Yes, somewhat, no, unclear)
        i. Are definitions given as to what each category means?
        ii. Are examples given of what each category means? (e.g., Autoimmune Condition (Lupus))
5. Does the data report include the U.S. Department of Health and Human Services' (HHS) "six minimum questions to ask about disability"? [32] (Yes, somewhat, no, unclear)
    a. (1) Are you deaf or do you have serious difficulty hearing?
    b. (2) Are you blind or do you have serious difficulty seeing, even when wearing glasses?
    c. (3) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
    d. (4) Do you have serious difficulty walking or climbing stairs?
    e. (5) Do you have difficulty dressing or bathing?
    f. (6) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

Results

Tables 2 and 3 present the findings from our analyses of the representation of disability-related data in engineering higher education contexts. Overall, there was a severe lack of reported disability-specific data. Only two of the nine sources we reviewed had disability data for higher education students [1], [2]. The "Diversity and STEM: Women, minorities and persons with disabilities" [1] report showcased a plethora of information regarding the representation of marginalized populations in STEM, such as workforce, salary, undergraduate and graduate

enrollment, and unemployment data. Within the higher education data shared, the report details specific gender, racial, and ethnicity breakdowns across several categories (i.e., bachelor's degrees earned, overall science and engineering degrees earned, and graduate enrollment data). However, for disabled individuals, the only available higher education data shared is the percentage of doctorates earned. And this is in a report entitled, "Women, minorities, and p*ersons with disabilities*" [emphasis added]. The "Digest of educational statistics" [2] report compiles statistical information across different sectors of American education, ranging from prekindergarten through graduate school. This report includes information ranging from the number of precollege and postsecondary institutions, teachers, enrollment data, and degrees conferred, in addition to federal funds for education, libraries, and other services. Across the breadth and scope of information provided, there were only two tables that contained both higher education and disability data (Tables 311.10 and 312.80).

Some of the remaining reports had disability information and higher education information but did not have any places where the categories overlapped [3]–[5]. For example, the "Report on the condition of education" [3] included disability demographic data, but the data reported came from disabled students who are covered under the Individuals with Disabilities Education Act (IDEA). Since IDEA only covers pre-college students [33], the reported disability data did not showcase higher education-specific demographic information.

Among the sources containing disability information [1]–[5], all employed person-first language. The two reports that included higher education-specific disability data used functional limitation language in their inclusion criteria, but adhered to person-first language within the reports themselves [1], [2]. Only one of these sources offering higher education-specific disability information provided a clear definition and conceptualization of disability [1]. Three other data sources offered vague definitions of disability, often relying on inclusion criteria from other programs (e.g., IDEA) to determine disability status [2]–[4]. Notably, the final report providing disability-related data [5] did not define disability whatsoever. Furthermore, only one report [3] categorized disabilities into distinct groups, and even then, it did so in only one section of the report. The remaining reports [1], [2], [4], [5] did not elaborate on different groupings of disabilities beyond the distinction between disabled and non-disabled individuals. Additionally, only one report [1] incorporated the U.S. Department of Health and Human Services' (HHS) "six minimum questions to ask about disability" [32]. While the "Digest of educational statistics" [2] included four out of six questions in one of its tables, none of these questions were present in another table containing disability and higher education-specific data. Moreover, two of the remaining sources did not utilize any of the six questions [3], [4]. The report, "Making visible the invisible" [5] did not specify its data sources, leaving uncertainty regarding whether it referenced the HHS questions.

Four data sources did not include any disability data [6]–[9]. The absence of disability data in these sources underscores a significant gap in the understanding and addressing of disabled students' needs within postsecondary engineering programs. Without such demographic information, it becomes challenging to accurately assess the representation of disabled students within postsecondary engineering programs, as well as these program's accessibility, inclusiveness, or lack thereof. The exclusion of disability-related data diminishes the visibility of disabled students in engineering. This exclusion from data sources explicitly focused on increasing diversity representation within STEM programs (e.g., [1]) emphasizes this disregard. Addressing this

omission is essential for fostering a more diverse and equitable academic environment that supports the needs of disabled students pursuing engineering education.

Table 2
An Overview of Data Sources that Excluded Disability

Questions	**Engineering and engineering technology by the numbers** [6]	**Annual report for The Spencer Foundation** [7]	**Higher education in science and engineering** [8]	**The state of U.S. science and engineering** [9]
(Q1) Is disability included as a demographic characteristic?	No	No	No	No
(Q2) Use of language	N/A	N/A	N/A	N/A
(Q3) Is a definition given for "disability" or how they conceptualized "disabled"?	N/A	N/A	N/A	N/A
(Q4) Disability desegregation	N/A	N/A	N/A	N/A
(Q5) Inclusion of the U.S. Department of Health and Human Services (HHS) "six minimum questions to ask about disability"	N/A	N/A	N/A	N/A

Discussion and Implications

On Disabled Students in Engineering Education

Our findings reveal the evident lack of representation of disabled students in large, higher education reporting bodies. These tables showcase the profound lack of data concerning disabled students as an entirety, let alone on students with specific disabilities or disability types (e.g., D/deaf, chronic illness, mental health, etc.). As such, the representation of the disabled community and its expansiveness becomes eradicated in engineering spaces, as we do not even know the breadth of disabilities that these students have. Without a comprehensive understanding of the diverse range of disabilities present within this community, it is impossible to adequately address their similarly uniquely diverse needs and experiences.

Furthermore, funding and support initiatives often rely on empirical evidence [30], [31]. Thus, the scarcity of information around disability could help to also explain the insufficient funding and support initiatives for disabled students in higher education. In higher education settings across the U.S., disabled students often lack dedicated cultural centers or communal spaces [34]. Instead, offices like Disability Resource Centers (DRCs) exist as bureaucratic entities that serve to provide legally mandated accommodations to students, and therefore rarely offer community [35]. The dearth of community also means that needed support beyond those that are legally required is rarely provided [35], [36]. This absence of community support compounds the challenges faced by disabled students, exacerbating their unmet needs beyond those related to accommodations [35], [36].

Table 3

An Overview of Data Sources that Included Disability

Questions	**Diversity in STEM** [1]	**Digest of education statistics** [2]	**Report on the condition of education** [3]	**Education across America** [4]	**Making visible the invisible** [5]
(Q1) Is disability included as a demographic characteristic?	Yes (but only for doctoral degrees conferred)	Yes (but data is only listed in Tables 311.10 and 312.80. Disability is not included in the actual report)	Yes (but only for disabilities covered under the IDEA legislation, which does not include postsecondary students)	Yes (but does only includes K-12 disability-related data)	Yes (but only includes STEM workforce disability-related data)
(Q2) Use of language	Person-first language, functional limitation (within the qualification criteria for "having a disability," but not within the report itself)	Person-first language, functional limitation (within the qualification criteria for "having a disability" in Table 311.10 but not within the report itself)	Person-first language	Person-first language	Person-first language
(Q3) Is a definition given for "disability" or how they conceptualized "disabled"?	Yes (provided six questions for "Defining Persons with at Least One Disability" and stated that anyone who responded "yes" to any of the six questions were considered to have a disability. The report also wrote, "Disability is defined as an individual reporting at least moderate difficulty on at least one of several tasks")	Somewhat (a definition is included in Table 311.10, but not in Table 312.80 or within the actual report. Definitions are included within the Appendix "Definitions" section. However, the disability definitions state that it includes those who receive services covered under IDEA legislation, which is only for P-12 students)	Somewhat (definitions are included in the Appendix "Definitions" section, but not the actual report. The definition section stated that students with disabilities who were included in this data were those who "identified as students with disabilities under IDEA, according to an IEP, IFSP, or a services plan")	Somewhat (definitions are included in the Appendix "Definitions" section, but not the actual report. The definition section stated that students with disabilities who were included in this data were those who "identified as students with disabilities under IDEA, according to an IEP, IFSP, or a services plan")	No
(Q4) Disability desegregation	No	No	Somewhat (the "Students with Disabilities" section reported disability-related data by disability type. However, other sections reported disability as a singular, overarching demographic category)	No	No
(Q5) Inclusion of the U.S. Department of Health and Human Services (HHS) "six minimum questions to ask about disability"	Yes	Somewhat (Table 311.10 uses four of the six questions but Table 312.80 uses none)	No	No	Unclear (does not report the specifics of data collection)

Much of the existing literature on engineering and disabilities tends to position disabled people as recipients of design rather than as engineers themselves [37]. The prevailing discourse within engineering education often overlooks the lived experiences and perspectives of disabled individuals as active contributors to the field (e.g., [38]). Instead, disabled students are frequently positioned as passive recipients of engineering solutions rather than as capable engineers in their own right [39]. Consequently, disabled engineering students are more likely to see other disabled people as subjects requiring engineering intervention rather than as potential peers and professionals within their field [37]. This perpetuates a systemic bias that undermines the agency and expertise of disabled engineers and further marginalizes their presence within engineering communities. By failing to recognize the diverse talents and contributions of disabled individuals, engineering education not only limits the representation of disabled professionals but also misses out on valuable insights and innovations that could enrich the field as a whole. Thus, there is an urgent need to shift the narrative surrounding disability in engineering towards one that acknowledges and celebrates the expertise, lived experience, and potential of disabled engineers.

On Disability Researchers in Engineering Education

The absence of statistical evidence regarding disabled students in engineering higher education creates challenges for researchers interested in studying this demographic. Our findings reveal that data on the number of disabled students enrolled in engineering programs is effectively nonexistent. Notably, the data that does exist offers little insight, as demonstrated by the fact that *only two out of over 800 tables* in the 2021 Digest of Educational Statistics [2] contain higher education disability data. We hope that this paper highlights the absence of this data and motivates researchers to undertake more comprehensive and rigorous data collection efforts on this population.

Researchers (particularly within engineering) often want to quantify populations [40]. However, this task becomes exceedingly difficult when it comes to the disabled population in higher education, given the dearth of available data. Simultaneously, DEI researchers often face scrutiny regarding their credibility [40]. The absence of data for an entire population not only discourages but also complicates advocacy-based research efforts around disability, it renders situations in which your credibility will now be called into question [41].

Additionally, funding opportunities for disability research remain limited and DEI funding sources often fail to include disabled people in their target research populations [18], [24], [25]. Demonstrating the need for funding proves difficult when we lack basic information about to disabled population [31], [42], such as the mere number of disabled students in higher education. Improved data collection on disabled student populations at the postsecondary level will play a crucial role in advocating for more funding opportunities by providing evidence of the existence and significance of this population to potential funders.

Moreover, the absence of robust data on disabled students in engineering higher education perpetuates systemic inequalities and inhibits efforts to promote inclusivity and accessibility within academic spaces [25], [43]. Without accurate and comprehensive information on the representation and experiences of disabled individuals in engineering programs, institutions may struggle to implement targeted support services and accommodations. This lack of data also hinders the identification of systemic barriers and the development of effective interventions to

address them [25]. By prioritizing thorough data collection and analysis, higher education stakeholders can better understand the challenges faced by disabled students in engineering education and work towards creating more equitable and supportive learning environments. This will in turn benefit disabled students while concomitantly broadening diversity, equity, and inclusion initiatives within engineering education.

Conclusion, Limitations, and Future Research

This paper critically examined the availability of disabled student data at postsecondary engineering programs in the US. We found that disability is largely excluded from large higher education datasets in the US, especially in STEM-specific data. We acknowledge that this paper looked only at large STEM education funder reports and data repositories. As a result, we are missing other large entities that are crucial to the capturing and reporting of disability-related data (e.g., higher education admission and enrollment data). Future work will seek to replicate this examination process across a wider range of reports and data sources. Future research will also work to create recommendations for cripping [44] future data collection efforts. Still, these findings offer valuable insights for policymakers, educators, and researchers seeking to enhance the representation and support of disabled students in engineering fields – ***starting with their mere inclusion in demographic data***.

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