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### **Describing Disability: Language and Models**

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## INTRODUCTION

People with disabilities compose a significant proportion of the U.S. population and the science, technology, engineering, and mathematics (STEM) workforce; however, disabled people are employed and compensated within in STEM fields at inequitable rates compared with their nondisabled counterparts. This paper introduces disability concepts and explores disability disparities in the context of postsecondary STEM education and the STEM workforce. Work and productivity have had a “long-standing role” in framing disability. Rose describes in particular, “In many cultures, disability has been characterized as the inability to do productive labor, a charge that has limited the citizenship and social standing of people with disabilities.” However, Rose continues, “In both the industrial and postindustrial eras, disabled people developed strategies that allowed them to enter—or remain—in the workforce” [1, 187]. In the United States, access to work for people with disabilities has been supported by laws, such as the Rehabilitation Act of 1973 (P.L. 93-112), the Americans with Disabilities Act (ADA) of 1990 (P.L. 101-336), and the ADA Amendments Act of 2008 (P.L. 110-325); however, the effect of these laws has been limited by other forces such as “judicial hostility and the failure to address employers’ prejudice” [1, 187]. Consequently, employment rates of disabled people of working age have not changed much in past decades.

This paper begins by providing definitions of common terms, including *disability* and *impairment*; *ableism*, *disableism*,<sup>1</sup> and *anti-ableism*; *accessibility* and *inclusion*; *accommodations* and *inclusive design*; and *stigma*. After that, it discusses the language used to describe disability;

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<sup>1</sup> There are two spelling conventions “disablism” and “disableism” that are used by various scholars, with both referring to discrimination against or exclusion of people with disabilities. In this publication, we defer to the author’s selected preference of the term *disableism*.

relevant U.S. laws; and a range of frameworks for understanding disability, including the medical, social, affirmative, tragedy, universal, and minority models, as well as the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health. These frameworks serve as a foundation for a discussion of critical disability studies, including critical disability theory, crip theory, Deaf epistemologies, and critical realism. Finally, the paper summarizes existing information about the participation of disabled persons in the STEM workforce and suggests topics for future research that is needed to fill knowledge gaps and policies to more fully include persons with disabilities in the STEM workforce.

Several limitations to the information presented in this paper are noted here. First, issues related to the intersection of individuals' social identities will receive limited attention. Individuals with the same disability have varying experiences based on other aspects of their identity, such as gender, race, ethnicity, nationality, socioeconomic status, and sexuality. However, these issues have received little attention to date. Second, the models and frameworks for disability discussed arise from Western or Global North cultures. Given the global nature of STEM, it would be useful to attend to Indigenous and Global South frameworks and models of disability as well. Finally, extant literature does not delve deeply into differences in disabled individuals' experiences based on age of acquiring impairment(s). These differences in disability experience affect how an individual experiences barriers and supports. Yet, much of the literature treats disability as a monolith.

## **DEFINITIONS**

### **Disability and Impairment**

The term disability is used in multiple contexts (e.g., medical, educational, and employment settings, and in government policies) and for different purposes (e.g., to assess the implications of chronic health conditions, to determine eligibility for disability benefits and support services, or to find an identity-based community). Operational definitions of disability vary by context but are typically linked with functional impairments and limitations in major life activities, such as work, schooling, self-care, and household maintenance. Across definitions, disability is defined as a deficit in relation to ability.

This paper uses the definition of disability in the Americans with Disabilities Act of 1990. According to the ADA National Network, this law defines a person with a disability as someone who has a physical or mental impairment that substantially limits one or more major life activities [2]. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability [2]. The ADA also makes it unlawful to discriminate against a person based on that person's association with a person with a disability [2].

### **Ableism and Disableism**

Disability is typically conceived as the opposite of ability or capability. Wolbring defines ableism as “a set of beliefs, processes and practices that produce—based on abilities one exhibits or values—a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others. This

preference for certain abilities over others leads to a labeling of real or perceived deviations from or lack of ‘essential’ abilities as a diminished state of being” [3]. He then contrasts ableism—“the valuing or obsession with ability”—with disableism, “discrimination against the ‘less able’” [3]. Whereas disableism negatively situates disability, ableism positively values ability [4].

Dolmage, writing in the context of academia, foregrounds ableism “not because disableism isn’t present in higher education—it absolutely is.... But academia powerfully mandates able-bodiedness and able-mindedness, as well as other forms of social and communicative hyperability, and this demand can best be defined as ableism. In fact, few cultural institutions do a better or more comprehensive job of promoting ableism” [4, 7]. Since disability is broadly constructed as an individual deficit of ability, it can be difficult for those within the academy to recognize ableism as problematic, leading to potential bias against disabled scientists and scholars, particularly in admissions, hiring, promotion, and tenure decisions.

Since academia is shaped by ableism, examples of ableism in higher education abound. James et al. interpret an introductory physics instructor’s surprise that a student the instructor perceived as “strong in the subject” could have a disability as an example of ableism [5]. In an interview, the student explained: “He [the instructor] thinks that ‘Oh, because she’s strong in the subject, she wouldn’t have a disability. She doesn’t need accommodations.’ So the fact that he found out, he was like ‘I’m so shocked, like.’ I guess he was being like biased or stereotypical” [5]. The authors interpret this as an example of the instructor only expecting able-bodied and able-minded people to succeed in the course. Coffie et al. identified evidence of ableism in the way that a well-meaning physics instructor, who had volunteered to participate in a faculty learning community about Universal Design for Learning, described students with disabilities.

For example, the instructor described some students as “not working well” with others regardless of the group and described some student groups as being “weighed down” by certain students [6]. Additionally, the instructor shared concerns that “accommodations aren’t really appropriate most of the time because if it takes you twice as long to do a test, that’s you know in real life if you’re working for a corporation, you don’t get twice as long to do your projects just because you have some diagnosed issue or something like that” [6, 110]. The authors interpret these as examples of ableism because the instructor frames the classroom context as neutral rather than recognizing the context was shaped by expectations that privilege certain abilities over others. This example also foregrounds how ableism can shape expectations about absenteeism (i.e., missing work) and presenteeism (i.e., showing up for work while sick, likely leading to reduced productivity) [7]. The instructor expresses an expectation that a disabled person is less productive than a person without disabilities.

In the book *(Un)learning Disability: Recognizing and Changing Restrictive Views of Student Ability*,” Baines reports on an ethnographic study with eight high school students labeled with learning disabilities [8]. Baines shares the experience of one student, with the pseudonym James: “James, who deeply despised being labeled with attention-deficit/hyperactivity disorder (ADHD), often said he failed to see the point of science class, because he was never going to be a “good science student.” Instead, he saw himself as a “scientist,” an identity that he did not think could exist within the confines of academic expectations” [8, 67]. This can be interpreted as an example of disableism, as Baines explains, “When a student with a disability is negatively perceived by those around him, he can be restricted in his access to valued opportunities that might be related to abilities he would like to develop in relation to personal goals” [8, 36]. While James was able to hold the duality of being *both* a “bad” science student *and* a “good” scientist,

many students would be *pushed out of STEM* by the “bad science student” message James received.

Exploring perceptions among professional geoscientists, Atchison and Libarkin found examples of views that may align with ableism about who could become a geoscientist [9]. In response to a prompt about the necessity of fieldwork in geoscience training, participants shared views such as “Unless one feels the work in its natural environment, nobody should aspire to call himself a geologist.” In this response, the participant constrains what it means to be a geoscientist by prioritizing abilities such as mobility and vision (and also reinforces gendered discrimination). On the other hand, other participants used an expansive framing of geoscience, such as “Laboratory and modeling are also ‘geoscience’ and also allow a standard career,” and in doing so decenter specific abilities [9].

Ableism may manifest in the charitable model of disability, which positions disability as a deficit and implies disabled people must rely on pity and charity from able-bodied others [10; 11]. In education, the charity model explains why able-bodied professors may receive recognition for providing access to a disabled student by innovating (or retrofitting) their class. For example, a literature review by Chini and Scanlon found that many articles about teaching physics with disabled students framed disabled students as a burden that sympathetic instructors would dedicate extra time and energy to support [12]. Such a framing ignores that education systems were designed to support the default able-bodied and able-minded student.

## Anti-Ableism

One can engage in anti-ableism by using strategies, theories, actions, and practices to actively dismantle abled privilege [13; 14]. The concept of anti-ableism parallels that of antiracism, which was taken up in the recent National Academies of Sciences, Engineering, and Medicine report *Advancing Antiracism, Diversity, Equity, and Inclusion in STEMM Organizations: Beyond Broadening Participation* [2]. In this report, the authoring committee defines *antiracist* as “to engage in an active, intentional, and dynamic set of actions that dismantle and disrupt the policies, practices, attitudes, cultures, and systems that confer power and privilege to White people over others” [2, 301]. In the same way, anti-ableism requires action and redistribution of power. Compared with ableism, the concept of anti-ableism is less developed in the context of the academy, so we need to look broadly for examples. Lalvani and Bacon, writing in the context of early childhood education, explain that “disrupting ableism can only be achieved if teachers position disability as a valued form of human diversity, create spaces for rethinking the constructs of disability and normalcy, and teach their students to embrace differences without stigmatizing them” [15, 89]. In the context of postsecondary education, Nieminen and Pesonen propose anti-ableism as a “systemic approach to both i) promoting the belonging of disabled students and ii) preventing the exclusion and marginalization of disabled students. Anti-ableism aims to disrupt the ideals of normalcy and productivity as often underlying teaching practices” [16, 3]. One may interpret the creation of an accessible periodic table that replaces the familiar letter symbols to identify the elements with Braille and 3-D printed sign language as an example of anti-ableism [17], and including embossed, large-font, high-contrast letter symbols would make this model periodic table more fully inclusive. Anti-ableist leaders could work toward a culture of sharing “access needs,” a



regular practice among the disability justice activist community [18]. Such access needs could include providing materials in plain text accessible to a screen reader or providing regular, short breaks in meetings or classes [18]. It is also important to recognize that all individuals have access needs, but some individuals' needs are met in the default environment [18]. For example, it is common to provide chairs during conference sessions with a series of oral presentations, which meets the common access need to sit. On the other hand, chairs are often not provided during poster sessions, where a presenter with a physical impairment may have the same access need. Additionally, the chairs provided during conference sessions are typically designed to fit a certain range of bodies, and options are not provided for individuals whose bodies do not conform to the standard chairs.

### **Accessibility**

As Williamson describes, “In its most literal form, ‘access’ describes the ability to enter into, move about within and operate the facilities of a site, and is associated with architectural features and technologies, including wheelchair ramps, widened toilet stalls, lever-shaped door handles, Braille lettering, and closed-caption video” [19, 15]. As David Rice, Branch Director of Special Emphasis Programs at the National Institutes of Health Office of Equity, Diversity, and Inclusion, who is deaf, observes, “Accessibility is traditionally associated with physical access, such as ramps, accessible parking, and auto-door openers. However, many do not realize that under Section 508 of the Rehabilitation Act of 1973, information and communications technology (ICT) must also be accessible for people with disabilities. Broadly, this means that the federal government must procure, create, use, and maintain ICT that is accessible to people with disabilities, regardless of whether they work for the federal government. An employee

should not have to ask for accommodation to ensure everything electronically is accessible and usable, because the law requires that all ICT be Section 508 compliant at all times” [20].

Access goes beyond physical access and access to information. For example, in the *Universal Design for Learning Guidelines Version 2.2*, CAST describes affective access (i.e., recruiting learners’ interest), perceptive access, and access related to physical access and expression [21]. Access can also include transportation and financial access. Additionally, individuals vary in their proficiency with access tools, resources, and technologies. For example, blind individuals may use a range of tools, including screen readers, screen magnifiers, and Braille. Thus, there is no one-size-fits-all approach to creating access.

### **Inclusion**

Some scholars consider inclusion to be distinct from access. In this view, access is about creating environments that are usable regardless of a person’s abilities. Inclusion, then, goes beyond access and usability to focus on “*how* cultural practices and norms foster communities and workplaces where everybody feels they can participate and be heard” [22]. Thus, inclusion can include improving hiring practices and making sure people with disabilities are represented in all aspects of an environment [22]. In a postsecondary STEM education setting, access may look like having the technology available for the sonification of data typically accessed visually and allowing blind students to use this equipment. Inclusion may look like including photos and biographies of scientists with disabilities, such as Wanda Díaz-Merced, an astronomer who uses data sonification, within department displays, and discussing how data sonification has benefited the science [23; 24].

## **Accommodations**

Accommodations are adjustments to the existing built physical and/or social environment to provide access for a disabled individual retroactively. In higher education, accommodations may include providing extra test time and a distraction-free testing environment for students with disabilities or providing a teaching assistant to assist a hard-of-hearing instructor with accessing questions during a large-enrollment course [25]. During professional conferences, accommodations may include designating a specific laptop to display CART (Communication Access Real-Time Translation) captioning for a single deaf participant. However, these practices can construct the disabled students and employees as the “problem to be fixed,” turning attention away from systemic solutions, which Nieminen identifies as an ableist agenda [16]. The “duty to accommodate” framework places the onus for accessing accommodations on the disabled individual. For example, Braun et al. describe the journey of a hypothetical deaf student enrolled in a university STEM course, which includes first interfacing with the university’s disability services office to request accommodations [26]. If the necessary accommodations are not provided, Braun et al. describe that the student should complain to the disability services office, potentially with faculty as an ally. If the university does not resolve the issue, the student will need to file a complaint with the Office of Civil Rights in the U.S. Department of Education [26]. The Office of Civil Rights will then need to conduct an investigation to decide whether to enforce accommodations [26]. The burden is thus on the student to request accommodations and escalate complaints if accommodations are not provided. Given the potential for ableism in the construction of disability accommodations, some prefer to conceive of “accessibility aids” or “accessibility supports” instead when engaging in this dialogue.

The ADA requires “reasonable accommodations” to provide access to spaces, careers, and education [19]. While the initial requirement to provide accommodations to employees has a short-term negative effect on the hiring of disabled people, the effect fades, likely as employers recognize that many accommodations have little or no cost [19]. For example, the Job Accommodation Network found for employers who responded to a survey about the cost of accommodation, 49 percent had no cost; 43.3 percent carried a one-time cost, with a median of \$300; and 7 percent required ongoing costs, with a median annual cost of \$3,750 [27].

### **Universal Design and Inclusive Design**

In contrast to individual accommodations, universal and inclusive design both position the built physical and social environment as the problem to be fixed. Universal design is defined as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” [28]. One common explanation of universal design elaborates the concept through seven principles: equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use [28]. Ron Mace, who coined the term universal design, pointed out that it is not “one size fits all,” as an environment that is barrier-free for one person can be a barrier for another. For example, the Accessible Periodic Table described above creates a barrier for individuals who do not know American Sign Language or Braille (in fact, this is likely a goal of the design to create a barrier for those who typically do not experience barriers). Examples of universal design include design choices listed under the “Accessibility” heading, above, when they are included in the *design* phase. Inclusive design for the STEM workforce includes designing laboratory equipment and spaces that can be used by individuals with a range

of bodies and abilities. Historically, laboratory equipment encodes expectations that able-bodied men will be manipulating the equipment, which may preclude others, such as women and disabled individuals, from using the equipment [29]. Inclusive design is typically considered to be similar to universal design, with the addition of the concept of “reasonable.” Persson et al. explain, “The phrase ‘reasonably possible’ expresses one of the main differences from other approaches, since ‘reasonably’ seems to suggest that the inclusion of people with disabilities can be disregarded if considered too difficult to achieve or too costly, whereas, for example, the United Nations’ Convention on the Rights of Persons with Disabilities claims these rights to be absolute and unconditional” [30].

### **Stigma**

Love describes stigma as “the disapproval and disadvantage that attach to people who are seen as different” as well as “part of the complex of factors that transform impairment into disability” [31, 173]. Stigma is pervasive in U.S. society and may cause disabled individuals to avoid disclosure and engage in secrecy and information management about their impairment(s). Individuals with nonapparent or “invisible” disabilities often attempt to “pass” as nondisabled to avoid the consequences of stigma [31]. Workers who attempt to pass as nondisabled may also not disclose their disability to their employer to avoid stigmatization [32; 33]. However, within the current accommodation framework, disabled individuals are unlikely to have access to accessibility supports from their employer or educational institution without disclosure.

## **DISABILITY LANGUAGE**

### **Use “Disability”**

Language is powerful and transient. The term disability has largely replaced the now outdated “handicapped” [34]. A variety of terms have been put forth as alternatives to disability, often to remove the negative associations of disability (e.g., differently abled or special needs); however, such terms are “considered euphemisms in disability culture, and have largely been received with scorn by disability advocates” [34, 113] as their effect is infantilizing and/or patronizing, revealing discomfort with disability [35]. Andrews et al. explain that “a common sentiment towards disabled people is, ‘I don’t think of you as disabled,’” which reveals “actual prejudices and biases against people with disabilities. Expressions of surprise upon learning about disabled people’s accomplishments and abilities or denial of disability identity are microaggressions, covert social experiences that indirectly or subtly insult the recipient” [34, 113]. Use disability.

### **Follow Individual Preferences about Person-First versus Identity-First Language**

There is no consensus on what language to use to describe people with disabilities, with preferences shaped by many factors, including specific impairments, age of disability onset, and generational cohort [34]. It is important to remember, as Shakespeare wrote, “While terminology is important, it is not [so] important as underlying values ... quibbling over ‘disabled people’ versus ‘people with disabilities’ is a diversion from making common cause to promote the inclusion and rights of disabled people” [36, 19]. As Andrews et al. write, “The language used to

describe diverse communities and the words selected by different cultures to describe themselves are constantly evolving, along with the attitudes of and toward these groups” [34, 112].

Historically, conceptions of disability were dominated by the moral and medical models, and the associated language tended to be negative and even dehumanizing, such as referring to people *as* their impairments (e.g., “a paraplegic”) [34]. Reacting to this trend, which could frame disabled individuals as homogeneous, people like Beatrice Wright advocated for “person-first” language “where the focus should be on the person, who literally comes before his or her disability” [34, 112]. Person-first language became the predominant style in the United States and is currently used by organizations such as the National Science Foundation, American Psychology Association, American Medical Association, and American Speech-Language-Hearing Association.

While person-first language still dominates many spaces, some disabled individuals prefer identity-first language. As Andrews et al. write, “Those who identify as part of contemporary disability culture often elect to identify as ‘disabled people,’ deliberately affirming and reclaiming disability identity” [34, 112]. Preference for identity-first language may be an intentional act to push back on tragic notions of disability as inherently negative and undesirable. For example, advocates in the neurodiversity movement may prefer “autistic person” (rather than “person with autism”) because the autistic neurotype is an essential part of the individual’s identity [34].

Sharif et al. developed an online survey to explore language preferences across many variables, including disability categories, gender, age, and country. At the time of writing, 519 people had responded to their survey, and 49 percent of respondents held a preference for identity-first language, 33 percent for person-first language, and 18 percent had no preference

[37]. On May 26, 2023, the survey had 975 respondents, and person-first and identity-first language had nearly equivalent support (40 percent and 39 percent, respectively). While Sharif et al. report differences in language preferences by disability category, some of these trends have changed in this data visualizer since the time of publication. One trend that has remained consistent is the difference in language preference across age categories, with respondents younger than 35 preferring identity-first language and respondents older than 50 preferring person-first language.

Since language preferences vary across individuals, one should ask about and use an individual's preferred language.

### **Avoid Harmful Language**

Beyond the person-first or identity-first debate, harmful language is still common in many outlets, including the general public and media. As in other minoritized communities, some members of the disability community have reclaimed language that was once viewed as wholly negative or pejorative. For example, as gay communities have reclaimed the label “queer,” some disabled individuals have reclaimed the term *crippled* as the label “crip” [38]. Andrews et al. write, “These efforts at reclamation are by no means universal, and can be controversial” [34, 112]. However, the common occurrence of using language to insult nondisabled people by calling them disabled is dehumanizing and unacceptable. Common insults use outdated language about intellectual disability (e.g., “idiot”) or invoke sensory impairments to reify the diminished status of disabled people (e.g., using “blind” for “oblivious,” “deaf” for “unawareness,” “lame” for “uninteresting”). Language often reinforces tragic views of disability, such as “afflicted with” and even “inspirational,” which is often used to inspire nondisabled



individuals at the expense of objectifying disabled people [34; 39]. One should educate oneself on harmful language and strive to remove such language from one's repertoire. The blog page *Ableism/Language* on AutisticHoya by Lydia X. Z. Brown is one starting point [40].

## **DISABILITY LAWS AND THE ACADEMY**

### **International Standards**

While legal requirements vary by country, international standards shape local laws. The United Nations Convention on the Rights of Persons with Disabilities (2008) states that co-signing countries should “ensure an inclusive education system at all levels and lifelong learning” to support the development of a sense of dignity, self-worth, personality, talents, creativity, and mental and physical abilities, such that disabled people can “participate effectively in a free society” [41]. The Web Content Accessibility Guidelines (WCAG), developed by the World Wide Web Consortium, or W3C, provide digital accessibility guidelines, which have been used as accessibility standards in national laws (see WCAG Web Accessibility Laws & Policies site for examples; [42]). EN 301 549 describes the accessibility requirements for ICT products and services in the European Union [43]. The Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired or Otherwise Print Disabled sets standards related to accessible-format book publishing [44].

## **Relevant Laws in the United States**

Title II of the ADA applies to state and local governments, including public institutions and national laboratories, and requires that people with disabilities can receive equal benefits and participate in the same programs as people without disabilities. Reasonable modifications can include allowing a person with diabetes to access snacks in a space that typically has a no-food policy, allowing service dogs in spaces with a no-pets policy, ensuring online forms are accessible to people who use screen readers and screen magnifiers, and allowing extended time on exams for individuals whose impairment's slow processing time [45].

Section 504 of the Rehabilitation Act of 1973 extends similar requirements of Title II of the ADA to all organizations that receive federal funding [46]. Section 225 of the Communications Act of 1934 (47 U.S.C. Section 151 et seq.), as amended, covers all hardware and software used for telecommunications, and requires such resources to be either accessible to people with disabilities or compatible with resources commonly used by people with disabilities [47]. The Architectural Barriers Act (ABA) of 1968 (42 U.S.C. Section 4151 et seq.) requires that buildings or facilities designed, built, or altered with federal funding after August 12, 1968, are accessible to people with disabilities, in accordance with standards further defined within the ABA [48].

## **Laws Do Not Create Full Inclusion**

Writing in the context of Canadian higher education, Prema and Dhand explicate that the existence of laws does not directly translate to full inclusion of disabled people because laws and codes require accommodations to be provided “until undue hardship,” which has been legally determined in terms of costs, potential funding sources, and health and safety requirements.

Thus, “educators are often unsure of how to apply the legal requirements of the duty to accommodate appropriately for students pursuing STEM, while balancing the factors of health, safety, and cost” [49, 123]. Since the laws do not create “positive obligations” to create access and inclusion, it is possible that individuals who do not complain will not have their rights enforced [49]. Individuals may fear they will be stigmatized for complaining, with potential implications for career advancement. For example, writing in the context of postsecondary education, Braun et al. describe that when an accommodation is not provided, a student must complain; they continue, “Faculty can helpfully advocate for the student, because the student may be wary of souring his or her relationship with the university” [26]. This tension extends to the relationship between a disabled employee and employer.

## **DISABILITY FRAMEWORKS**

Two frameworks for disability, the medical model and the social model, have dominated Western thought [50]. More recently, scholars have drawn attention to the need to use multiple disability frameworks to investigate the experiences of disabled individuals [51; 52; 53]). This section highlights both commonly used disability frameworks and how scholars are using newer frameworks and combinations of frameworks to empower disabled people.

### **Two Common Models: The Medical Model and the Social Model**

Goldiner associates the medical and social models with addressing questions about the *cause* of disabled people’s social disadvantage and exclusion [53]. The medical model situates disability within the individual [50] and as the result of impairments [51]. The medical model is

shaped by a positivist framework [51], where individuals are described in clinical, medical terms [50], and the ultimate goal is rooted in ableist notions of treatment and cure [51]. Ideas aligned with the medical model shape public policies, such as the U.S. Social Security Administration's definition of disability "as an inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment" (42 U.S.C. 423 (d) (1) in [53]). The emphasis is on the "impairments as the cause of [disabled people's] disadvantage in social participation" [53]. Potential benefits of the medical model include improvements in the lives of disabled people through medical and technological advances, while potential negative effects include paternalism and pathologization [50].

Conversely, the social model "views disability as a social construct" [51, 21] and "attributes disabled people's disadvantage to their surrounding environment" [53]. The environment includes physical components as well as social, political, and economic factors [51, 21]. In this view, rather than loss of participation resulting directly from impairments, environmental conditions, such as inadequate accommodations or inaccessible equipment, create a loss of participation. As stated by the Union of the Physically Impaired Against Segregation in 1976, "It is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society" [54]. In line with the social model, the responsibility for providing access to participation is shared by society in removing social and structural barriers. Potential benefits of the social model include the integration of disability as a positive part of one's identity, leading to a sense of belonging and pride, as well as a clear distinction between malleable social barriers and unmalleable impairments [50]. Potential negative effects include

the need for strong self-advocacy skills, the downplay of effects of impairment on everyday life [50], as well as discounting values such as interdependence and human dignity [51].

## **Additional Models**

### **Affirmative Model versus Tragedy Model**

Goldiner proposes a method for multifactorial consideration of disability frameworks by disentangling the primary focus of a disability model as cause, effect, and the dis/ability divide [53]. The social and medical models, described above, address the *cause* of disability. The tragedy and affirmative model mark opposing views of the *effect* dimension. The tragedy model claims that impairment negatively affects quality of life and well-being, making one worse off overall. Taken to its extreme, the tragedy model undergirds attempts to prevent bringing more disabled people into being. The tragedy model can also manifest as presenting successful disabled people as “inspirational.” On the other end of the effect spectrum, the affirmative model allows the possibility for impairment to have a positive effect on an individual’s life. As summarized by Goldiner, “Enduring the changes that impairment causes to the lived body sometimes necessitates adopting different ways of doing things and therefore enable the acquisition of valuable perspectives on life and the world. Impairments could have the liberating effect of freeing people from restrictive social expectations” [53].

### **Minority Model versus Universal Model**

Disability frameworks may also diverge in whether they suppose a distinction between disabled people and nondisabled people [53]. The minority model claims a distinction between

disabled people and nondisabled people, though the marker of disability varies across specific instantiations of the minority model in combination with other disability models. For example, a view based on the minority and medical models may frame disabled people as only those whose impairments limit their participation in society, while a cluster of the minority and tragedy models posits that disabled people are only those whose impairments negatively affect their life. Such models undergird the common notion that nearsighted people are not disabled in societies where corrective lenses are available to enable their full participation in society [53]. An important commonality across versions of the minority model is “calling for practices that single out only disabled people as beneficiaries” [53]. Under the minority model, an individual may access certain benefits through the ADA by “proving” they are disabled. For example, while remote work became the norm under COVID-19–related protections, when such protections were reduced, some employees had to demonstrate a health impairment to be granted remote work as an accommodation.

Conversely, the universal model “rejects the dichotomy between disabled and non-disabled people, and instead conceives disability as a universal human condition” [53]. Advocates for the universal model of disability, such as Zola, highlight that everyone eventually becomes disabled during their lifespan. Others, like Bickenbach, conceive of all humans on an ability spectrum since “no human has a complete repertoire of abilities, suitable for permutations of the physical and social environment” (Bickenbach in [53]). Under the cluster of the universal and social models, practices such as “universal design” aim to construct institutions and policies that take into account the range of human variation. Under the universal model, an employer may allow all employees the option to work from home, which could benefit both employees with

diagnosed disabilities as well as nondisabled employees experiencing temporary illness, family obligations, or other situations that could be alleviated by working from home.

## **World Health Organization: International Classification of Functioning, Disability, and Health**

WHO established the International Classification of Functioning, Disability, and Health (ICF) in their 2011 *World Report on Disability*. The ICF is a biopsychological model that aims to bridge the medical and social models of disablement (Shaun Grech [50, 20]). It describes how health conditions impair physical and mental function, how functional limitations affect the ability to perform basic activities, and how these activity limitations can restrict participation in community, social, and civic life. It also asserts that the type and severity of activity limitations and restricted participation levels can be moderated by environmental as well as personal factors. The Centers for Disease Control and Prevention note that relevant environment attributes “range from physical factors (such as climate, terrain or building design) to social factors (such as attitudes, institutions, and laws),” and that “interaction with environmental factors is an essential aspect of the scientific understanding of ‘functioning and disability’” [55].

## **CRITICAL DISABILITY STUDIES**

### **Critical Disability Theory**

Critical disability theory foregrounds situated and localized knowledge, centers the voices of disabled people, and calls upon nondisabled individuals to use disability research as a tool to confront ableism [51]. For example, Peña calls on higher education researchers to

“identify regulatory undertones that serve to control people with disabilities; critique disabling structures that permeate the educational landscape ... and incorporate the voices and interests of people with disabilities in decision-making processes” [51, 18]. Disability is viewed as fluid and temporal, and critical disability scholars highlight the importance of the intersectionality of disability with other identities.

### **Crip Studies**

Crip studies is an approach within critical disability studies that frames disability as “(a) a negated identity as a consequence of an emphasis on compulsory able-bodiedness and simultaneously (b) a subversive position that disruptively crip normative standards in society” [50, 193]. In this way, crip activism aligns with other activist communities, such as the queer community, and proposes an affirmative identity in contrast to, and in challenge to, traditional negative connotations of disability.

### **Critical Realism**

Critical realism is grounded by three principles: intransitivity, transfactuality, and stratification. Intransitivity is the stance that reality and causal relationships exist whether we are aware of them or not. Transfactuality is that causal relationships are somewhat reliable, allowing useful predictions of natural and social systems. Stratification is that reality exists at multiple levels, such that “disabilities exist on molecular, biological, physiological, emotional, interactional, institutional, and cultural levels simultaneously” [51, 26]. Critical realism supports interpretations of diverse experiences of individuals with similar impairments by recognizing that while similarity exists at the biological level, differences may exist at other levels, such as



differences in coping at the psychological level and differences in support at the social level [51]. For example, two individuals with identical audiograms indicating deafness may vary in their use of spoken language and signed language depending on the age of onset of deafness, family use of spoken and signed language, and educational setting; such differences could manifest in different methods of career navigation despite similarities in biological impairment.

### **Deaf Epistemologies**

Deaf epistemologies encourage nondeficit thinking, through concepts such as “Deaf Gain”<sup>2</sup> to counter “hearing loss.” Brown explains, “Deaf Gain is an avenue to interrogate the negative ways in which society interprets hearing loss and more deeply explores the possibility that Deaf people positively contribute sensory and cognitive diversity to the world” [51, 29]. This stance pushes “researchers and participants to see themselves as complex people who are not solely defined by the environment of their ability to engage in environments” [51, 29].

### **DisCrit**

DisCrit combines aspects of critical race theory and disability studies to support “dual analysis of race and ability” [57, 9]. The developers of DisCrit propose seven tenants, summarized below [57, 19]:

1. “Racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of normalcy.”

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<sup>2</sup> “Deaf” with a capital *D* to refer to the cultural group of people who share a common language (i.e., American Sign Language, knowledge, beliefs, and practices [56].

2. Singular notions of identity (i.e., race *or* dis/ability *or* gender, etc.) are not as useful as multidimensional conceptions of identity.
3. While race and ability are socially constructed, there are “material and psychological impacts of being labeled as raced or dis/abled.”
4. Voices of marginalized populations are centered.
5. Race and dis/ability “have been used separately and together to deny the rights of some citizens.”
6. Whiteness and Ability operate as Property. “Gains for people labeled with dis/abilities have largely been made as the result of interest convergence of White, middle-class citizens.”
7. “DisCrit requires activism and supports all forms of resistance.”

Thus, DisCrit provides a framework to simultaneously explore the implications of race and ability, which is essential in STEM, where both people with disabilities and people of color have been marginalized. DisCrit points out that the experiences of individuals who are both disabled *and* persons of color will differ from those of individuals with only one of these minoritized identities.

## STATISTICS ON DISABILITY IN STEM

### Operationalizations of Disability

Statistics on workforce participation of disabled people in STEM are provided in several reports, including the biennial *Women, Minorities, and Persons with Disabilities in Science and Engineering* (WMPDSE) report, most recently published in 2023 [58]. Disability disparities in employment in the STEM fields are broadly consistent with 2022 estimates published by the Bureau of Labor Statistics (BLS), which indicate that 23.1 percent of the civilian noninstitutionalized population of adults (aged 16 or older) with disabilities are employed, compared with 77.1 percent of adults without disabilities [59].

Both the WMPDSE and the BLS use data from the Census Bureau's Current Population Survey (CPS), which now includes six standard disability questions:

1. Do you have difficulty dressing or bathing?
2. Are you deaf or do you have serious difficulty hearing?
3. Are you blind or do you have serious difficulty seeing even when wearing glasses?
4. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?
5. Do you have serious difficulty walking or climbing stairs?
6. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

If a respondent answers yes to any of these questions, they are considered to have a disability. It is important to note that these questions are also included in other federal surveys like the American Community Survey, which was used to estimate the widely cited adult disability prevalence rate of 25 percent) [60]. This emerging consistency in operationalization is attributable to Section 4302 of the 2010 Affordable Care Act (P.L. 111-148), which required uniform federal standards for the collection of data on race, ethnicity, gender, sexual orientation, primary language, and disability status [61]. Recent findings from these reports are as follows.

### **Statistics Reported in the 2023 *WMPDSE* Report**

Data tables in the *WMPDSE* report statistics related to employment, degrees awarded, and graduate education. Highlights from these data are summarized below.

#### *Employment*

People with disabilities are underrepresented in the STEM workforce. In one 2021 report, while 9 percent of the U.S. population identified with one or more disability in 2021, only 3 percent of the STEM<sup>3</sup> workforce identified with one or more disability at this time. (Note, statistics vary across surveys, so it is difficult to compare across different surveys.) This is similar to the workforce overall but lags the labor force, in which 4 percent of individuals have one or more disability. While the STEM workforce overall grew from 2011 to 2021, the share of STEM workforce who have one or more disabilities remained constant at 3 percent. While 24 percent of nondisabled workers work in STEM occupations, slightly fewer (21 percent) of

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<sup>3</sup> This section uses “STEM” (science, technology, engineering, and mathematics) to indicate that the data are cited from a report that did not investigate medical careers.

disabled workers do, suggesting disabled workers are employed in STEM occupations at a slightly lower rate than nondisabled workers.

### *Employment Sectors in the WMPDSE – Classifications Used to Describe Employment Trends*

The *WMPDSE* report uses a range of categories to describe employment. At a larger scale, the report describes careers in the following categories: all occupations, science and engineering (S&E) occupations, science and engineering–related occupations, and nonscience and engineering occupations. Within these categories, science and engineering occupations consist of biological, agricultural, and other life scientists; computer and information scientists; mathematicians; physical scientists; psychologists; engineers; and postsecondary teachers. S&E-related careers include health-related occupations, S&E managers, S&E pre-college teachers, S&E technologists, and other S&E-related occupations. *Nonscience* and engineering occupations include arts, humanities, and related occupations; management-related occupations; non-S&E managers; non-S&E postsecondary or pre-college teachers; sales and marketing occupations; social service and related occupations; and other non-S&E occupations. Another way the report divides the STEM workforce into S&E occupations, S&E-related occupations, and middle-skill occupations, which do not require a bachelor’s degree. These groupings will be used in the following sections to describe employment trends.

### *Employment Status Statistics*

The *WMPDSE* provides data about the employment status of scientists and engineers with and without disabilities stratified by age, summarized in Table 1. This data shows that the percentage of scientists and engineers who identify with a disability increases as the population

ages (9.9 percent for 29 and under to 19.5 percent for 50-75). However, the report finds that “in terms of age—and contrary to what is typically believed—STEM workers with at least one disability are not overwhelmingly concentrated in the older age groups. According to the 2021 CPS, among the STEM workforce ages 18 to 74 with one or more disabilities, 18% were in the early stages of their career (ages 18 to 34), 39% were midcareer (ages 35 to 54), and 43% were in the later stages of their career (age 55 and older)” [58, 13]. We note that these age bands are so broad as to make interpretation difficult to impossible.

Across all ages, scientists and engineers with a disability less frequently report full-time employment and more frequently report they are not employed, but seeking employment, than those without a disability. Scientists and engineers employed part-time in S&E-related occupations who identified with a disability reported wanting full-time work about twice as often as those who did not identify with a disability (28 percent vs. 15 percent). Thus, while disabled STEM professionals may find employment, that employment may not meet their economic and personal needs. For example, disabled faculty may be hired into contingent or adjunct positions rather than full-time, permanent positions, which may affect their access to health care and other employment benefits [62].

In 2021, unemployment was higher among those with a disability (5.3 percent) than those without a disability (3.6 percent) in STEM occupations. However, unemployment was higher and the gap between those with and without disabilities was larger in non-STEM occupations (11.2 percent vs. 6.5 percent). Thus, it is essential to make STEM training accessible, as such training may provide protection from unemployment for disabled individuals.

**TABLE 1** Employment Status of Scientists and Engineers by Disability Status and Age

<b>Age group</b>	<b>Disability status</b>	<b>Population N</b>	<b>Full-time work (%)</b>	<b>Part-time work (%)</b>	<b>Seeking employment (%)</b>	<b>Not seeking employment (%)</b>	<b>Retired (%)</b>
<b>TOTAL</b>	Without disability	32,973,000	70.0	11.2	3.3	5.3	10.2
	With disability	5,290,000	53.7	12.2	5.5	7.9	20.7
<b>29 and under</b>	Without disability	5,014,000	75.0	11.8	4.9	8.3	D
	With disability	549,000	68.5	11.5	6.7	13.5	D
<b>30–39</b>	Without disability	8,617,000	81.1	9.5	3.0	6.4	S
	With disability	867,000	72.3	13.1	8.4	6.0	S
<b>40–49</b>	Without disability	6,875,000	81.1	10.0	2.6	5.9	0.3
	With disability	854,000	72.7	10.5	4.9	10.8	1.1
<b>50–75</b>	Without disability	12,467,000	54.2	12.8	3.2	3.1	26.7
	With disability	3,020,000	40.2	12.6	4.	6.7	36.0

The *WMPDSE* also provides data for the sector of employment stratified by broad occupation and disability status. Data by sector is summarized in Table 2, which demonstrates that scientists and engineers with a disability are more frequently employed (by greater than 1 percent) by self-employment or in the state or local government and less frequently employed (by greater than 1 percent) in the nonprofit and universities and 4-year college sectors. Some disabled STEM professionals may find that industry, particularly a large company, is more accessible than academia (for example, see [63]).

**TABLE 2** Employment Sector of Employed Scientists and Engineers by Disability Status

<b>Sector</b>	<b>Total (% by sector)</b>	<b>Without disability (% by sector)</b>	<b>With disability (% by sector)</b>
<b>TOTAL N</b>	<b>30,255,000</b>	<b>26,775,675</b>	<b>3,479,325</b>
Business or industry	55.1	55.0	55.7
Federal government	4.7	4.6	5.4
Nonprofit	11.8	12.1	9.3
Self-employed	5.5	5.2	7.5
State or local government	6.0	5.9	7.0
Universities and 4-year colleges	8.0	8.1	7.0
Other educational institutions	9.0	9.1	8.1

*Median Wage and Salary Earnings of the STEM Workforce with One or More Disabilities*

Individuals with one or more disabilities have higher median wages in the STEM workforce (\$57,000) than outside of the STEM workforce (\$30,000). However, individuals with one or more disabilities make less than those without disabilities in both STEM (\$57,000 vs. \$65,000) and non-STEM (\$30,000 vs. \$41,000) occupations. Median wages varied with a similar trend across STEM occupation type, with the highest median wages for both individuals without disabilities and individuals with one or more disability in STEM occupations, followed by S&E-related occupations, and then middle-skill occupations (see above for definitions of these career groupings). While individuals with and without disabilities report similar median wages (around \$90,000) for S&E occupations, individuals with disabilities earned less than those without disabilities in S&E-related occupations (~\$53,200 and \$67,800, respectively) and middle-skill occupations (~\$45,000 and ~\$50,000, respectively). Earning a bachelor's degree or higher



increased median wage for both those with a disability (\$46,000 without a bachelor's degree vs. \$90,000 with a bachelor's degree or higher) and without a disability (\$50,000 without a bachelor's degree vs. \$82,000 with a bachelor's degree or higher). However, individuals without a disability reported higher median wages both with and without a bachelor's degree.

### *STEM Workforce and Educational Degree Level*

STEM workforce members who had one or more disabilities are overrepresented in careers that typically do not require a bachelor's degree (called middle-skill careers in the *WMPDSE*) and the non-S&E workforce. This may be related to degrees earned by STEM workforce members with one or more disabilities, as a lower proportion of the STEM workforce with one or more disabilities has a bachelor's degree (35 percent) compared with the nondisabled STEM workforce (51 percent).

### **Degrees Awarded**

The *WMPDSE* states, "Compared with data for other groups, data on postsecondary degrees earned by persons with disabilities are limited" [58, 56]. The report includes data on doctorate recipients by selected field and disability status as well as disaggregated by type of disability and type of disability disaggregated by sex, citizenship, ethnicity, and race. (See Tables 2-5 and 2-6 in the *WMPDSE* for this data.) While data is presented for associate's degrees, bachelor's degrees, and master's degrees earned by field, sex, citizenship, and race and ethnicity data is not reported for these degrees by disability status. Thus, one cannot track how the share of individuals in STEM degree programs changes across educational levels from the *WMPDSE*. However, these data across degree ranks are gathered from the Integrated Postsecondary

Education Data System (IPEDS), National Center for Science and Engineering Statistics (NCSES) Survey of Earned Doctorates, with baseline demographic data from the Current Population Study for ages 18–34.

### *Graduate Degrees Earned*

Graduate students with one or more disabilities make up a smaller share of doctoral recipients in S&E fields (11 percent) compared with non-S&E fields (13 percent). Individuals with one or more disabilities made up the highest share of graduate degrees in psychology and social sciences (13 percent) and the lowest share in engineering (8 percent). Undergraduates with one or more disabilities make up about 25 percent of undergraduate STEM majors, so these statistics suggest a large decrease in the representation of disabled individuals among graduate degree recipients compared with undergraduate [64].

### *Graduate Enrollment*

While data is presented for enrollment in science and engineering graduate degree programs by field, sex, degree, citizenship, ethnicity, and race, this data is not reported for graduate enrollment by disability status. Data is presented for full-time graduate students primarily supported by the federal government by enrollment level, field, and sex, but not by disability status. The NCSES Survey of Graduate Students and Postdocs, or GSS, does not provide enrollment data by disability status.

## **Other Sources for Statistics on Disability**

### **National Longitudinal Transition Study and Educational Longitudinal Study**

Lee has published multiple studies investigating STEM enrollment patterns for students with and without disabilities with data extracted from the National Longitudinal Transition Study-2, or NLTS2, and Educational Longitudinal Study of 2002, ELS 02/06 [65, 66, 67]. Using these surveys, Lee found that students with disabilities more frequently selected STEM majors than students without disabilities; more students with disabilities enrolled in STEM majors at 2-year colleges compared with students without disabilities; and female students less frequently enrolled in STEM majors among both students with and students without disabilities [65]. In further analysis, Lee found that “students with disabilities from lower-income backgrounds were significantly more likely to choose STEM majors compared to their counterparts” at 4-year, vocational, and technical postsecondary institutions [66, 261].

### **National Center for Education Statistics**

The National Center for Education Statistics reports statistics on the percentage of undergraduate students who identified with a disability, the distribution of the reported main type of disability, and additional information about institutional and student characteristics. These data suggest several changes over recent years. First, the percentage of undergraduates who identify with any disability has nearly doubled, from 11.1 percent in 2011 to 19.5 percent in 2015. Second, among students who identified with one or more disabilities, substantial increases were observed in the share of students identifying with attention-deficit/hyperactivity disorder and mental illness/depression. Note, this does not indicate a decrease in the absolute number of students with sensory impairments, since the total number of students who identify with

disabilities has increased with time. These trends are in line with the expanding interpretation of “disability” within the ADA [68].

## **Other Relevant Disability Statistics**

### *Medical School Enrollment*

A 2019 study by the Association of American Medical Colleges found that only 2.7 percent of medical school students disclosed a disability [64]. This is substantially lower than the 19.5 percent recently reported in the undergraduate population observed across degree programs and the 11 percent of graduate degrees earned in S&E fields.

### *STEM Principal Investigators*

Data on the percentage of funded investigators in STEM in the United States are low. From 2008 to 2018, 2 percent of investigators funded through the National Institutes of Health reported having a disability [69]. Within the National Science Foundation, less than 1 percent of funded investigators reported having a disability. Additional information about the percentage of proposals submitted and the review rating within demographic groups is reported in the National Science Foundation’s Merit Review Process FY 2020 Digest [70].

## **Suggested Next Steps for STEM**

### **Implement Multiple Models of Disability to Improve the Well-Being of Disabled People and Disrupt Ableism in STEM**

Historically, discussions about disability in the United States have been framed, whether explicitly or implicitly, through the medical model of disability. It is time to move beyond individual-facing solutions, such as accommodations and special programs for disabled people in STEM, to systemic solutions. The recent Dear Colleague Letter (NSF 21-110) and solicitation (NSF-593) on Workplace Equity for Persons with Disabilities in STEM and STEM Education takes a step in this direction by centering the social model of disability and calling for research to identify barriers for persons with disabilities in the STEM community. Research is needed that questions the assumptions of the traditions of STEM education and the STEM workforce to identify more accessible and inclusive environments and policies. Like other aspects of identity, disability is not a monolith. Additional models discussed in this chapter and beyond, such as models emerging from Indigenous cultures and the Global South, should be leveraged to envision a flexible STEM community.

### **Collect Data to Measure Change**

In *Indicators for Monitoring Undergraduate STEM Education*, a consensus study report of the National Academies of Sciences, Engineering, and Medicine, the Committee on Developing Indicators for Undergraduate STEM Education called for disability status to be included in the demographic data collected by national data systems to monitor progress toward equity, diversity, and inclusion for STEM students and instructors [71]. The committee explored

existing major data sources on undergraduate education and found that several did not allow disaggregation for disability status, including IPEDS. Other datasets, like the Beginning Postsecondary Survey, which at the time of the report was available for students who started higher education in the 2003–2004 academic year, does provide data disaggregated by disability status. These efforts to collect data that allow comparison at various education levels and into the workforce should be continued and expanded with shared definitions for disability and STEM and additional detail about age of disability onset and other social identities to attend to intersectionality.

However, simply counting the number of people with disabilities in the STEM community is not enough. While representation is important and increased representation may indicate improvements in access, well-being for disabled people in STEM goes beyond access to inclusion and more. New data should be envisioned and collected in line with the goal to disrupt ableism in STEM.

### **Model and Support Disability Disclosure**

Data are only useful if they are a valid and reliable representation of people's experiences. However, as discussed in this paper, challenges like stigma may lead to individuals choosing to “pass” as abled rather than reveal their disabilities. Universities and federal research agencies such as the National Academies need to model disability disclosure by high-ranking members being transparent about their personal experiences with disability. Additionally, professional and scientific organizations need to support disability disclosure by making the purpose of collection and plans for the use of the data transparent.

## **Investigate Equity within Your Organization**

Disabled STEM professionals are overrepresented in lower-skilled STEM careers and make lower wages than their nondisabled counterparts. Organizations should investigate their pay scales to ensure disabled employees have equivalent wages to their nondisabled peers and investigate their performance review metrics for potential biases that may contribute to pay-scale inequities.

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