

## **Academic pipeline for scientists** with disabilities

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The business model for organizational diversity states that "diverse" organizations have a competitive advantage over non-"diverse organizations. These advantages arise from increased creativity,1 problem solving,2,3 decision making,4 and overall quality of results,5 among other observed outcomes. Within academia, increasing diversity benefits performance and persistence of students by reducing the deleterious effects of solo status (being the only representative of a social group)/tokenism (member of a minority social group in a given organization) and stereotype threat.

People with disabilities are an underrepresented group in materials science and, more broadly, in science, technology, engineering, and mathematics (STEM) fields. However, inclusion of persons with disabilities is often left out in the drive to increase diversity. Efforts to increase diversity in PhD-level leadership positions have not resulted in significant gains among people who identify as having a disability. This article presents the status of people with disabilities in the STEM pipeline, examines reasons why there has been little progress in increasing doctorate degree attainment for people with disabilities in STEM, and discusses possible ways to get people with disabilities to become more active in advanced STEM careers. While the data presented here come solely from the United States and lack granularity to pinpoint the status of persons with disabilities in materials science and engineering, the concepts addressed are transferable to both materials science and engineering, in particular, and to other countries in general.

#### **Degree attainment in STEM fields**

Accurate numbers for people with disabilities are difficult to obtain and vary with the survey methodology, how disability is defined, and how the questions are phrased. The US Census Bureau 2011–2015 American Community Survey estimates 5.8% of the noninstitutionalized population of US citizens and permanent residents between the ages of 18 and 34 years have a disability.6 The US Census Bureau 2010 Survey of Income and Program Participation estimates that 12.2% of the noninstitutionalized US population between ages 6 and 14 years have a disability,7 and 16.6% of those 21 to 64 years working age in the US population have a disability. At the same time, approximately 9% of K-12 students are enrolled in Individuals with Disabilities Education Act (IDEA) programs. 9 The IDEA data are perhaps the most reliable and informative metric because they hinge on the actual percentage of students who receive classroom accommodations for a disability; "disability" is functionally defined as an impairment that requires accommodations for the student to reach his/her educational potential. Table I lists the distribution of specific measures of disabilities among grade-school-aged children and highlights the difficulty in quantifying the number of people with a disability.8 It is unclear how a person with an amputated arm, severe depression, or anxiety would fit in this rubric. This distribution would change, and numbers would generally increase among an older population.

There is a leaky pipeline in STEM degree attainment for students with disabilities. Representation among enrolled STEM undergraduate and graduate students dropped from 10% to 6%, respectively.<sup>10</sup> Ultimately, people with disabilities account for less than 2% of STEM doctorates earned by US citizens or permanent residents. 10,11 Worse yet, based on the Survey of Earned Doctorates data, the percentage of STEM PhD degrees earned by people with disabilities has not increased since the passage of the Americans with Disabilities Act (ADA) in 1990.\* Figure 1 presents data (as a percentage) for US citizens and permanent residents earning doctoral degrees at US institutions. If the data were renormalized for US citizens and permanent residents with disabilities earning STEM doctoral degrees as a percentage of total STEM doctoral degrees conferred at US institutions, the time trend would be negative. That is to say, the number of foreign national students earning US STEM doctorate degrees is

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<sup>\*</sup> The Americans with Disabilities Act of 1990 is a civil rights law that prohibits discrimination based on disability.

increasing faster than the number of US citizens and permanent residents earning STEM doctorate degrees (see Figure 2). During this time, a slow but steady increase in the percentage of degrees earned by both Black and Hispanic students has been realized, but not for Native Americans or persons with disabilities. It is noteworthy that the percentage of all US STEM doctorates earned by Black and Hispanic citizens plateaued from 2003 to 2008 when the number of non-US citizens earning STEM doctorates at US institutions was rapidly increasing. Reasons for the relative longitudinal success of the Black and Hispanic populations compared to the Native American community and persons with disabilities is neither well understood nor well studied.

It can be asked, what should the percentage of STEM doctorates earned by persons with disabilities be? Embedded in this question is the intuitive thought that by having a disability, a significant fraction of this group would naturally not have the mental (or physical or psychological, etc.) stamina necessary to meet the minimum requirements. The argument follows that the expected participation rate for persons with disabilities should be significantly lower than the proportional 10% of the population because some (most?) people with disabilities are not suitable for higher education.

The question then can be asked, are there arbitrary organizational or cultural structures that unnecessarily inhibit the performance of people with disabilities in STEM fields? Such an

Type of Impairment	Children Ages 5–14 Years
Difficulty doing regular schoolwork	6.2%
Learning disability	1.9%
Attention deficit hyperactivity disorder	5.1%
Intellectual disability (mental retardation)	0.4%
Other developmental disability or condition	4.5%
Difficulty seeing letters or words Severe Not severe	0.3% 0.6%
Difficulty hearing conversation Severe Not severe	0.1% 0.5%
Difficulty having speech understood Severe Not severe	0.4% 1.6%
Difficulty walking or running Use wheelchair or similar device Use a cane, crutches, or walker	1.6% 0.2% 0.1%

**Table I.** Prevalence of specific measures of disabilities among children younger than 15 years in the United States.<sup>8</sup> This gives a snapshot of the distribution of disabilities that may be encountered in an educational setting. As the population ages, the prevalence will shift and increase in most cases.

alternative phrasing of the question neither assumes inherent limitations on one's capacity to excel nor presupposes a defined set of acceptable pathways toward success. In this light, it is worthwhile to investigate potential societal and structural factors that may be impacting the performance and persistence of people with disabilities in STEM fields, and consider equitable means to support the inclusion of people with disabilities in STEM.

# Factors influencing decreased participation of persons with disabilities

There is a vicious cycle for persons with disabilities interested in STEM.12 Many do not achieve their educational goals and become underemployed or unemployed. The April 2018 labor force participation rate for persons with disabilities in the United States is only 20.9% with an 8.0% unemployment rate, compared to 68.3% and 3.5%, respectively, for people without disabilities.<sup>13</sup> Among the employed, there is a 4% salary gap for those younger than 29 years of age with and without disabilities. This gap increases to 13% in the prime earning period between 40 and 49 years old.10 Employment outcomes for persons with disabilities have not improved since 1990, and between 2008 and 2010, workers with disabilities left the workforce at five times the average rate. 14 The consequent absence of successful persons with disabilities in prominent positions fails to provide the role models necessary to break societal prejudices or to serve as avatars for the next generation of students with disabilities.

This disparate outcome for students with disabilities does not result from a lack of interest in STEM fields by persons with disabilities. Students with disabilities desire to pursue a STEM degree at approximately the same rate as students without disabilities at the time of high school/college transition (21.7% versus 23.1%) and undergraduate/graduate transition (20.3% versus 21.3%). There is, however, a larger dropout rate for persons with disabilities following each transition.

The transition from high school to college is difficult for many students, particularly for students with disabilities. Most students struggle with the transition from the relatively structured high school/family setting to the new freedoms of being on their own. The life and study skills needed in high school are not necessarily adequate for the university/dorm setting. In high school, US students with disabilities are granted accommodations based on their Section 504 (S504) plan or Individualized Education Plan (IEP) determined by a panel of parents, teachers, and educational support staff; often students are not consulted while determining what accommodations will be implemented. In the college or university setting, the student is expected to assume leadership in anticipating and negotiating needed accommodations for classes and within the community—often for the first time and in addition to the stresses experienced during such a transition for all students. Centralized disability support services (DSS) do not offer the level of assistance that one may expect; the inherent role of DSS is institutional ADA compliance, not advocacy for students' needs.

Once students fall behind their peers, they are less likely to persist through graduation. Unfortunately, only 24% of postsecondary students who received S504/IEP support in high school

## CIVETSITY IN MATERIALS SCIENCE & ENGINEERING



registered with Disability Student Services (DSS), as they exist in most US universities, prior to the start of classes, and only 60% of registered students at four-year colleges received accommodations.15 Thus, few students register to receive the support needed to successfully launch a STEM career.

The University of Delaware (UD) is typical of a major research institution. Across all students, UD performs comparably to the national average, with a 25% initial enrollment in STEM, a 52% graduation rate in STEM, and 20% of undergraduate degrees awarded in STEM fields.16 The 13% STEM dropout rate after the first year is primarily migration to other majors. Investigation of descriptive variables for the leaky pipeline indicated that having a first year GPA below 3.0 was associated with both switching from a STEM major and dropping out of UD. Failure to adequately secure

needed accommodations places students with disabilities in an early academic hole that is difficult to escape. Of the 248 STEM students registered with DSS at UD, 149 have a current GPA below 3.0. Failure to successfully navigate the first year of college positions students with disabilities on track to neither persist in STEM nor actualize their career potential.

Societal factors contribute to persons with disabilities not seeking needed accommodations and contribute to feeling socially isolated. People with disabilities are caught between two communities and tend to identify with their race and gender. Disability is a descriptive characteristic. However, society tends to view people with disabilities through the prism of ability. For this reason, people with disabilities tend not to form a local supportive community in the manner of other underrepresented groups. It is instructive to note how this perception of one's self plays into the language of identity. Only people with disabilities use "person first" language—I'm a chemist with a disability that considers the disability ancillary to one's sense of identity. All other classifications define and take precedent over the person—I'm a heterosexual, white, male chemist. Additionally, the descriptor for disability is inherently negative; the personal identity is being described by what they are presumed not to be.

There is still a significant degree of societal shame and distrust associated with having a disability that further drives peoples with disabilities away from a supportive community. Many parents and persons with disabilities are still grappling with what is "wrong" with the person. This leads to a late diagnosis and

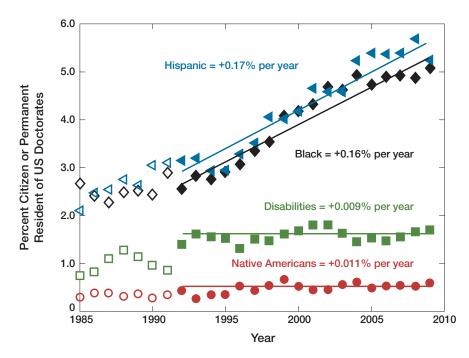


Figure 1. Longitudinal trends for STEM doctorates received by four different underrepresented groups. Open symbols represent data for years prior to the Americans with Disabilities Act (ADA). Closed symbols represent post-ADA data. Least squares trend lines fit to post-ADA data show no statistical increase in percent of STEM doctorates earned by US citizens or permanent residents with disabilities. Data from 2010 and beyond are not included because the Survey of Earned Doctorates changed the definition of disability in the questionnaire.

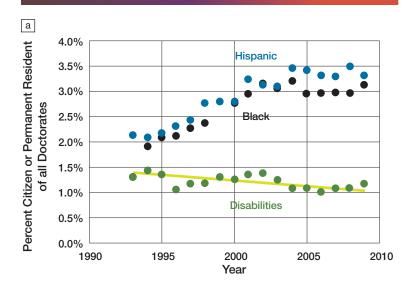
delivery of accommodations only after the student has fallen behind his/her full potential. Even with people appropriately diagnosed, proof that any accommodations are needed must be medically supported. And this, still, is often met with skepticism. While the need for accommodations for a person with visual, hearing, or mobility impairments are generally obvious, the need to accommodate people with less apparent disabilities (e.g., learning, depression, or anxiety) are often questioned, and the inclusion of people with "non-neurotypical" disabilities (e.g., autism, Tourette syndrome, or bipolar issues) is often socially resisted.

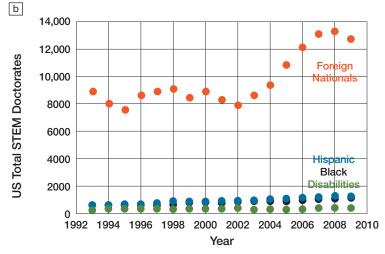
One significant consequence of the "vicious cycle" hindering degree attainment and the lack of a true "disability community" is the effective social isolation experienced by people with disabilities. The impacts of being a member of solo or token status (less than 15% representation) have been studied for the last 30 years.<sup>17</sup> Solo/token status has documented effects on the members of the minority group:

- 1. Inducing feelings of high visibility that leads to added stress and performance pressure
- 2. Increasing polarization between the two groups that leads to feelings of isolation
- 3. Self-modification of the minority group's behavior toward the majority group's stereotype of the minority group.<sup>17</sup>

A marked decrease in memory and cognitive processing ability among underrepresented minorities experiencing solo/ token status has also been documented. 18-20 It has been noted that solo status can lead to "stereotype threat"—a situation where individuals perceive that their actions will confirm stereotypes about their group. <sup>21,22</sup> Both solo status and stereotype threat lead to decreased performance across different practical performance metrics. <sup>23–26</sup> In general, solo status and stereotype threat are additive, <sup>21,24</sup> affecting members of low-status groups (the disability community in this case) to a much greater extent than members of higher status groups. <sup>27,28</sup> One proposed mechanism is decreased performance expectancies by members of disadvantaged groups in solo status situations. <sup>29</sup> Members of disadvantaged groups have a more negative reaction to the possibility of solo status <sup>30</sup> and develop more negative performance expectancies <sup>31</sup> than do members of privileged groups. Performance expectancies are a better predictor of actual performance than solo status. <sup>21</sup>

Students with disabilities are more likely to attend two-year institutions (47%) than four-year institutions (42%), compared





**Figure 2.** (a) Longitudinal trend for STEM doctorates earned at US institutions by US citizens or permanent residents who are Hispanic, black, or identify as having a disability as a percentage of total STEM doctorates conferred. (b) Trend of total STEM doctorates earned by these groups plus the total STEM doctorates earned by non-US citizens or permanent residents from US institutions.

to nondisabled students who are more likely to attend four-year institutions (47%) than two-year institutions (42%).<sup>32</sup> At the same time, students with disabilities are less likely to attend universities full-time, full-year (36.6%) than nondisabled counterparts (41.8%). They are more likely to attend school part-time or part-year (63.4%) than students without a reported disability (58.2%).<sup>32</sup> Part-time students and students at two-year institutions are less likely to be exposed to research opportunities than their counterparts enrolled full-time at a four-year institution: 7.5% of graduate students with disabilities age 23 years or younger compared to 17.6% of graduate students without self-identified disabilities. The 23-year-old mark is significant because this is the age that one would start graduate school when finishing an undergraduate degree in 4 or 5 years.<sup>33</sup> Consequently, US citizens and permanent residents enrolled in science and engineering

doctorate programs are less likely to be supported by a research assistantship if they have an identified disability (16.4%) than those with no reported disability (24.4%).<sup>34</sup> This further propagates along one's career for opportunities to be on the best projects, write highly cited papers, receive awards, and land the best or most visible jobs.

# Ideas to increase participation of persons with disabilities in STEM fields

Even though, or perhaps because, I have a disability—I broke my neck playing flag (American) football my freshman (first) year of college-I have struggled with justifying to myself what the appropriate interaction should be between a person with a disability who wants to be a fully integrated and contributing member of society, and a society that must change, or otherwise deviate from the status quo, to accommodate the inclusion by a person with a disability. As noted previously, there is a solid business case to be proffered as to why inclusion is beneficial to society. And moral cases can be made as well, be it allowing everyone to strive toward their full potential, supporting the dignity of living a productive life, or simply helping the disadvantaged and disenfranchised to fully participate in society's bounty. Yet, the question remains. What are some simple guidelines to better facilitate the true inclusion of people with disabilities in STEM careers with maximum benefit and minimum effort for both the people with disabilities and society in general? My thoughts are not unique, and many have been similarly expressed by others in different formats.<sup>35,36</sup>

# Recognize that a "disability" is situationally dependent

Persons with disabilities often differentiate between a "disability" and an "impairment." An impairment is the clinical description of a loss of function or negative deviation from an accepted

## CIVETSITY IN MATERIALS SCIENCE & ENGINEERING



population norm. A disability is a negative consequence of how an impairment interacts, or is viewed to interact, with the environment or society. Usually a disability needs an accommodation by society to enable full inclusion by the person. An impairment might be a disability in one situation but not another—a scientist with a mobility impairment might have issues with materials synthesis in a clean room, but needs no accommodations running a microscopy facility.

The severity of a disability may decrease over time as technology improves—the impact of hearing impairments has lessened as hearing aids and cochlear implants have advanced; technologies are on the horizon for similar breakthroughs with visual impairments. If an impairment affects enough people, it is not a dis-

ability—no one can see in the deep UV, far IR, or emitted electrons; we all use technology to accommodate our limitations. The disability may be created by (arbitrary) choices—how information is chosen to be stored, disseminated, and presented has differing impacts on people with visual, hearing, or learning impairments. For example, I had a student with a processing disorder; the wiring in his brain made reading very difficult. However, he excelled in organic chemistry and math because the complex written information was presented symbolically, not linguistically.

#### Focus on the ability, not the impairment

The American Chemical Society's Leadership Development System offers a short course on Extraordinary Leaders based on the Zenger and Folkman model for leadership excellence.<sup>37</sup> This model states that there are a small, finite number of skills that are instrumental to success in any given field. To become an extraordinary leader in that field, a person needs to excel at two or three core areas. Deficiencies in other skills are not important, as long as the skill is not absolutely critical to and an essential aspect of the job. In other words, hire people based on their abilities and place them in situations that play to their strengths and avoid exploiting their weaknesses. People naturally specialize as their career progresses; they gravitate toward or are directed to tasks that best align with their strengths and avoid those where they are more likely to struggle relative to their peers. For persons with disabilities, this progression to specialization is more prominent early in their careers. A person with a visual or mobility impairment may gravitate to computerbased aspects of the field. Persons with other disabilities may prefer more tactile jobs that require less writing. In this regard, persons with disabilities are no different than persons without disabilities except for societal perceptions. A person without a disability is implicitly given credit for their potential—all the

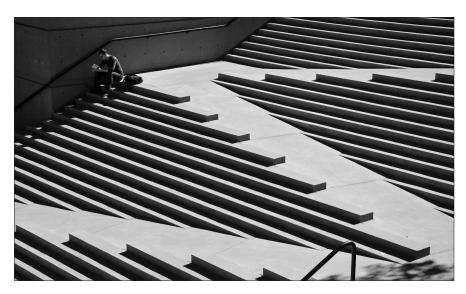


Figure 3. A visual representation of universal physical access in this photo of the blended ramp and steps at Vancouver, British Columbia's Robson Square, designed by Canadian architect Arthur C. Frickson in 1980.

things they could become even though they may not, while a person with a disability is penalized upfront for anything they cannot do, even though they may never be asked.

#### Remove unnecessary barriers and prejudices

In social justice advocacy circles, there is a famous graphic describing the difference between equality and equity. The picture shows three people of different heights watching a baseball game over a wooden fence; the tallest person can clearly see over the fence, while two progressively shorter people cannot. In the first frame, each person is given a box on which to stand. While this elevates the middle person enough to see over the fence, the tallest person does not need the box and the box is not sufficiently high to help the shortest person. This illustrates a concept of "equality"; all persons are provided equal access to resources regardless of their situational needs. The second panel redistributes the three boxes. The tallest person does not need a box to see over the wooden fence, and the shortest person needs two boxes based upon situational need. In this panel, the boxes are distributed based on "equity," where each person gets the accommodations needed for the opportunity to see the game. The graphic argues that "equity" is better than "equality" when the goal is to support the success of all members of an organization. The dedication of resources to implement ADA accommodations, family leave policies, and selectively flexible schedules are possible examples of equity. People get access to these resources only when they need them.

However, in its original form, this "equality versus equity" graphic misses the root cause of the problem—the wooden fence! Instead of questioning the proper allocation of boxes, the viewer should question the need for a wooden fence. Were the opaque wooden fence replaced with a chain-link fence, fitted with plexiglass windows or removed entirely, no accommodations would be

needed! This analogy translates directly to the workplace, lab, or classroom. When confronted with the need for an accommodation, think both about "How can we make this situation work for this individual?" and "Is this situation really necessary?" The need for an accommodation may be subverted by reimagining past decisions such as the location of equipment in the lab or the assignment of responsibilities among staffed positions.

#### Create universal design that benefits everybody

"Universal Design" is the philosophy that products and environments should be usable by all people, to the greatest extent possible, without the need for further adaptation.<sup>38,39</sup> Thus, an environment imagined that makes life easier for all users, not just people with disabilities is the goal of Universal Design. Universal Design is most often considered in physical spaces (see Figure 3). Automatic door openers, curb cuts, and adjustableheight counters are prevalent both around the research lab and around the town. These implementations are essential features for accessibility for persons with mobility impairments. In the lab, these are also widely used by staff with carts, people carrying equipment, and workers who may be significantly shorter or taller than average. However, Universal Design extends beyond the physical space to policies and procedures, to the access and delivery of information, and to organization of staff. Universal Design principles include equitable use, flexibility in use, simple and intuitive design, easy access to information, and tolerance for error. 40 An environment imagined by Universal Design principles philosophically reimagines the physical, logistical, and organizational order of the workplace for the benefit of all users.

#### Understand that every situation is unique

It is impractical to assume a one-size-fits-all approach to accommodations, so an open mind and open dialogue should be established. There is a wide range of impairments and disabilities that are too numerous to catalog; Table I provides only a partial list of disability types tracked by the Census Bureau in children. Having a disability is not a static event; many disabilities are transient, others vary over time and/or in terms of impact. Some people acquire disabilities and will approach the onset of a disability with varying degrees of acceptance. Some people learn to cope, compensate, or heal such that their impairment is gradually considered less of a disability. Life situations outside of school or work may change and cause a disability to become more or less of a factor for a while. Accommodations needed for one job may not directly translate to a new set of responsibilities. Two people with very similar disabilities may respond differently based on personalities or current life situations. In other words, the intersection between impairment and the world for people with disabilities is no less diverse than the intersection between adversity and the world for anyone. And this diversity adds to the diversity that strengthens any organization.

#### **Encourage inclusion**

It is widely accepted that members of minority groups often need extra encouragement to apply for career advancement opportunities. Most professional societies have supported initiatives to have more women and minorities apply or be nominated for awards or opportunities. However, persons with disabilities are often left out of these considerations. A noteworthy exception is Project Entry Point of AAAS (American Association for the Advancement of Science) that places undergraduate and graduate STEM majors with disabilities in paid industrial internships. While explicit encouragement through one-on-one communication and mentoring is great, even passive encouragement through a blanket US Equal Employment Opportunity Commission (EEOC) inclusivity statement sends a message that people with disabilities will be offered a fair hearing. I surveyed the web presence of 30 of the 2018 NSF Research Experience for Undergraduate (REU) sites in the Division of Materials Research at the National Science Foundation (NSF). REU programs are excellent means for undergraduate students coming from small colleges to get the research experience needed for admission to top graduate programs. Of 30 programs, 14 (47%) had no EEOC statement encouraging underrepresented groups to apply. (Curiously, the REU sites at the top 10 universities were least likely to have EEOC statements on the REU page.) Seven of the 30 programs (23%) had blanket statements encouraging all underrepresented groups to apply. Women were specifically encouraged to apply on 9 (30%) sites, minorities on 7 (23%), persons with disabilities on 5 (17%), and veterans on 1 (3%).

#### Realize that disabled does not mean incapable

Treat the person with a disability the same as everyone else. Encourage open dialogue and ask the person with a disability what they need to succeed, then provide them the needed resources and/or place them in the right situation. In many cases, the needed accommodation is simple and inexpensive. In other instances, the person with the disability can find an "outside the box" adaptation. Often these accommodations make life easier for others too. It is part of how a diverse organization becomes more creative and resilient while increasing performance.

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## CIVETSITY IN MATERIALS SCIENCE & ENGINEERING



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