# Disrupting Ableism and Advancing STEM

Promoting the Success of People with Disabilities in the STEM Workforce

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Board on Higher Education and Workforce

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### Acronyms and Abbreviations

AAAS American Association for the Advancement of Science

ADA Americans with Disabilities Act

ADD attention-deficit disorder

ADEA Age Discrimination in Employment Act of 1967

ADHD attention-deficit/hyperactivity disorder

AGU American Geophysical Union

AI artificial intelligence

AIM Apprenticeship Inclusion Models

APS American Physical Society

ARIA Accessibility, Research and International Affairs

ASCE American Society of Civil Engineers

ASL American Sign Language

AUCD Association of University Centers on Disabilities

CAIR Center for Accessibility and Inclusion Research
CART Communication Access Real-Time Translation
CDID Center for Discovery, Innovation, and Development
CIMER Center for the Improvement of Mentored Experiences in

Research

CNIB Canadian National Institute for the Blind

COMBINE Computational Modeling for BioInterface Engineering

DEI diversity, equity, and inclusion

DEIA diversity, equity, inclusion, and accessibility

DOD U.S. Department of Defense

DO-IT Disabilities, Opportunities, Internetworking, and

Technology

DOL U.S. Department of Labor
DPI Disabled Peoples' International
DRP disability resource provider

EAC Empower Ability Consulting, Inc.

EARN Employer Assistance and Resource Network
EDU Directorate for STEM Education (NSF)

EEOC U.S. Equal Employment Opportunity Commission EES Division for Equity of Excellence in STEM (NSF)

EGO European Gravitational Observatory

GSS Graduate Students and Postdoctorates in Science and

Engineering

HMS Harvard Medical School

HR human resources

IEP Individualized Education Program

IPEDS Integrated Postsecondary Education Data System

ISEED Inclusive STEMM Ecosystems for Equity and Diversity

LGBTQIA+ lesbian, gay, bisexual, transgender, queer/questioning,

intersex, ally/asexual, and other sexual and gender

identities

LHON Leber's hereditary optic neuropathy

LU-RRTC Rehabilitation Research and Training Center on Research

and Capacity Building for Minority Entities at Langston

University

MSU Michigan State University

NAS National Academy of Sciences

NDMC National Disability Mentoring Coalition
NHGRI National Human Genome Research Institute

NICHD Eunice Kennedy Shriver National Institute of Child

Health and Human Development

NIDILRR National Institute on Disability, Independent Living, and

Rehabilitation Research

NIH National Institutes of Health NSF U.S. National Science Foundation

ODEP Office of Disability Employment Policy

OSU Ohio State University

PDM Process Driven Math

RIT Rochester Institute of Technology

RRTC Rehabilitation Research and Training Center

SDS Student Disability Services

STAMP Science, Technology, Accessibility, Mathematics, and

Public Health

STEM science, technology, engineering, and mathematics STEMM science, technology, engineering, mathematics, and

medicine

TPI The Precisionists, Inc.

UC University of California
UDL universal design for learning
UMass University of Massachusetts
USU Utah State University

VA U.S. Department of Veterans Affairs

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#### Introduction

## BACKGROUND AND MOTIVATION FOR THE WORKSHOP SERIES

People with disabilities are the largest minority group in the United States. While nothing about science, technology, engineering, and mathematics (STEM) education, jobs, or workplaces would seem to inherently exclude people with disabilities, in practice, stigma and discrimination continue to limit opportunities for disabled people to fully contribute to and be successful in the STEM ecosystem. The planning committee for Beyond Compliance: Promoting the Success of People with Disabilities in the STEM Workforce of the National Academies of Sciences, Engineering, and Medicine, with funding from the U.S. National Science Foundation, organized a hybrid national leadership summit and virtual workshop series to address and explore issues of accessibility and inclusivity in STEM workplaces. Across the 5 days of workshops, dozens of panelists spoke about their personal and professional experiences of ableism and barriers to full participation in the STEM workforce, as well as identified positive examples of mentorship and efforts to create fully inclusive STEM spaces in education, labs, the private sector, and professional development settings.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> In the development of this workshop series, universal design and accessibility consultants from the DO-IT Center at the University of Washington were hired to help create the most inclusive event possible. As a supplement to this workshop series, DO-IT authored a paper that describes how the design and delivery of accessible events

The planning committee included STEM educators, researchers, private-sector trainees, and advocates, all of whom identify as having a disability. The committee designed the discussions for a wide range of people involved or interested in the STEM ecosystem, said Bonnielin Swenor, chair of the committee and director of the Johns Hopkins Disability Health Research Center, including trainees, researchers, policymakers, and those in professional organizations, private-sector jobs, nonprofits, and more. The discussions were intended to be welcoming for both people new to discussions of disability and anti-ableism and those who have made it their life's work, she added.

#### RECURRING TERMS AND THEMES

Speakers across the workshop series discussed a variety of terms and concepts around disability. While other chapters will feature speakers who further define and expand on some of these concepts in detail, including discussions of commissioned papers, a few common terms and themes are shared here with speaker-offered examples to place all discussion comments in context.

#### Ableism and Disableism<sup>2</sup>

Ableism is a type of bias or prejudice that favors able-bodied people, while disableism disfavors disabled people or discriminates against them. Further distinctions between these two biases and examples are discussed in depth in Chapter 3, where Jacquelyn Chini, professor of physics and undergraduate program associate director at the University of Central Florida, noted that ableism comes with "the assumption, again possibly unexamined, that nondisabled people are inherently superior to disabled people" and often happens when educational and workforce spaces assume no people with disabilities are present or fail to consider them.

can help to promote a culture of equity and inclusion. This paper is available at https://nap.nationalacademies.org/resource/27245.

<sup>&</sup>lt;sup>2</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."

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#### Strengths Mindset or Perspective

A strengths mindset is understanding, identifying, and promoting the unique contributions or benefits that people with disabilities bring to an educational or workplace setting. Planning committee member Jordan Rodriguez said that many companies and people think of disabilities from a deficit perspective rather than a strengths mindset, for example, "This Blind person uses a screen reader, so they can read text a lot faster than most people, and actually are better at picking up on typos" and other errors. Caroline Solomon, Director of the School of Science, Technology, Accessibility, Mathematics, and Public Health; professor of biology; and Interim Public Health Program Director at Gallaudet University, also gave the example of deaf researchers being able to communicate underwater during field scuba experiments, something that is inaccessible to hearing people who do not sign.

#### **Universal Design**

Universal design is a process or system that designs for all abilities, whether in physical spaces or in curricula. A commonly cited example by workshop speakers of positive outcome for universal design is the "curbcut effect." Mariah Lynn Arral, National Institutes of Health fellow and doctoral candidate at Carnegie Mellon University, described the eponymous curb-cut effect: providing accessibility for wheelchair users may be the motivation behind putting curb-cuts in sidewalks, but the change positively affects a variety of people, including parents with strollers, people carrying luggage and grocery carts, and those with temporary injuries. Marcia McNutt, president of the National Academy of Sciences, also gave an example of universal design on oceanographic ships that improved accessibility for people with mobility limitations but were also beneficial for all passengers. "It made the ships more navigable; it made them easier places to work," she said. (See Chapter 4 for an in-depth discussion of universal design for curricula.)

#### ORGANIZATION OF THE WORKSHOP SERIES AND PROCEEDINGS

The workshop series was designed, in partnership with the DO-IT Center at the University of Washington, to be as fully accessible as possible. The national summit had both in-person and virtual attendance options, and the four remaining workshops were all virtual.

Throughout the 5 days of the event, American Sign Language (ASL) interpretation and communication access real-time translation (CART) were provided, as well as real-time captions on the streamed video. Agendas with large text were posted on the website ahead of the workshops. During the leadership summit at the National Academies' Keck Center, attendees were able to use a quiet room and overflow space, with different temperatures, and they had access to refrigerators, freezers, and small sensory and stimming aids. All sessions were recorded and posted online with captions and ASL interpretation intact.

Speakers varied in how they described disability, some using person-first language (i.e., "a person with a disability"), while others used identity-first language (i.e., "a disabled person"). These proceedings reflect the mix of language used throughout the workshop series, including an individual speaker's preference, if specified. Each speaker also gave a visual description of themself as part of their introduction to support access for those with low or no vision. These visual descriptions have not been replicated in the proceedings, and disclosure of disability is included when relevant to the speaker's quoted comments.

This proceedings is organized into nine chapters, each covering a broad topic of discussion during the workshop event. Chapter 2 covers a high-level discussion with McNutt and Karen Marrongelle, chief operating officer of the U.S. National Science Foundation, as well as a discussion identifying what equity could mean for science in general and disabled scientists specifically. Chapter 3 introduces a paper on language models of disability commissioned for the workshop, and panelists' reflections on these models. Chapter 4 focuses on cultivating accessibility in educational spaces and pathways. Chapter 5 focuses on disabled students' lived experience in education and the transition to work. Chapter 6 focuses on mentorship across the STEM ecosystem, both in education and the workforce. Chapter 7 introduces a paper on workforce barriers and reimagining access in the workplace. Chapter 8 discusses creating disability-inclusive workforces and workplaces from a variety of perspectives. Chapter 9 covers reflections on the workshop from all committee members, as well as calls to action.

#### OPENING REMARKS

Swenor opened the leadership summit by saying these discussions were happening at "what feels like a really important moment." The COVID-19 pandemic, climate change, and advances in AI (artificial intelligence), show

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how STEM affects lives every day, Swenor said, and how the United States needs to take advantage of advancing science and innovation the best it can. "We know that that will take all of us, an all-hands-on-deck approach," she said, adding that it is going to take "tearing down the barriers that have kept so many people out, including people with disabilities."

As a scientist with a disability, she has spent much of her career trying to "enhance inclusion of people with disabilities in STEM." The barriers for scientists with disabilities are "formidable" and challenges exist across the ecosystem, she added, from education to getting a job to entering leadership. It is an inconvenient truth that STEM has "not been designed for us. It's actually been designed to keep us out," Swenor said. Most of those working in science with disabilities are doing so "not because we have overcome anything but because we have persisted. Persisted in a system that does not assume we should be here or that we will be here." While persistence is often viewed as a positive attribute, "we really have to think deeper ... and realize that for those that haven't had to persist in the same way, there is a role and responsibility to change the system," she said. "We have taken, head on, the idea that people with disabilities are lesser ... and attack the notions that including people with disabilities is just too complicated, is inconvenient or even too expensive." It is "beyond time" to reimagine STEM so that people with disabilities are included from the start, she continued, "not just because it is the right thing to do but because it is good for science."

Swenor identified that, over the course of the event, speakers would be discussing what disability means to people with disabilities, how the barriers to STEM are exponentially greater for people with disabilities from other underrepresented groups, and how to improve the STEM ecosystem to make sure people with disabilities feel like they belong.

## Toward Disrupting Ableism and Advancing STEM

#### LEADERSHIP DISCUSSION

The national leadership summit began with a discussion between the chair of the Beyond Compliance: Promoting the Success of People with Disabilities in the STEM Workforce planning committee, Bonnielin Swenor, Marcia McNutt, president of the National Academy of Sciences (NAS), and Karen Marrongelle, chief operating officer of the U.S. National Science Foundation (NSF). Swenor asked Marrongelle to share some background on NSF's work on disability inclusion in science, technology, engineering, and mathematics (STEM).

NSF has a "long history" of supporting disability inclusion, Marrongelle said. In 2023, they have programs and funding opportunities that include rehabilitation research, STEM, education research, use-inspired solutions to enhance quality of life, and workplace equity research. In May 2023, NSF issued a new solicitation: Workplace equity for persons with disabilities in STEM and STEM education. "It is going to invest in and support projects that focus on a fundamental, applied, and translational research that advance knowledge and practice around diverse, equitable, inclusive, and accessible STEM and STEM education workplaces," Marrongelle said, including postsecondary training environments for persons with disabilities. The solicitation is building upon a "Dear Colleague" letter NSF issued in August 2021, encouraging submission of new proposals, or supplemental requests

<sup>&</sup>lt;sup>1</sup> See https://www.nsf.gov/pubs/2023/nsf23593/nsf23593.htm.

to existing awards, to encourage the engagement of students, postdoctoral scholars, faculty, and staff with disabilities.

In 1992, NSF funded the University of Washington's Disabilities, Opportunities, Internetworking, and Technology (DO-IT) Center, which is now a "nationally recognized resource for empowering persons with disabilities in STEM and STEM education," Marrongelle said. More recently, NSF has also funded an AI (Artificial Intelligence) Institute led by the University of Buffalo to use artificial intelligence to develop better solutions for children with specific speech language needs, and, through its convergence accelerator program, has 16 projects developing "use-inspired solutions to enhance quality of life and employment opportunities for persons with disabilities." Marrongelle said this was not an exhaustive list of NSF funding for disability inclusion but some of the more recent examples.

#### Why Now?

Swenor asked McNutt about the timing for the National Academies of Sciences, Engineering, and Medicine getting involved in the effort to disrupt ableism. The National Academies have been very focused on the issue of where the scientific workforce for tomorrow is going to come from, McNutt said. There is a realization that if science does not pull in the full talents of everyone—women, underrepresented minorities, and people with disabilities—"we certainly aren't going to remain a science powerhouse." McNutt added that she was old enough to remember when "as a woman studying physics in college, [she] was as rare as someone with a disability in a physics lab," as well as the negative assumptions that were being made about her.

"Fast-forward to today and we find women in research labs of all disciplines and places all over the world, and it is no longer an anomaly," McNutt said. "We have to imagine that same future for people with disabilities." Disability inclusion has not been addressed head-on, but she said she was "hoping that this meeting will be a launchpad for all of us to take that more seriously."

#### **Disrupting Ableism**

Marrongelle agreed with McNutt about becoming more intentional with who is included in STEM disciplines and the STEM workforce for "the U.S. scientific enterprise to continue to thrive." She added that NSF's

director, Sethuraman Panchanathan, "passionately believes in this idea that anyone, anywhere—no matter who they are, where they live, [or] what they look like—they have innovative ideas to contribute to STEM." It is up to us, she added, to ensure those ideas can get included in the ecosystem.

But at least three things, among many others, are needed to disrupt ableism in STEM, Marrongelle said. First, strengthen multiple pathways into STEM fields: "We know now that any individual's pathway into STEM takes twists and turns," she said. "And it's rare that two people's paths look exactly alike." If someone needs to take time off or is entering the field later in life, "we need to ensure ... that there is a way in" as well as encourage new solutions to allow students and researchers to fully engage in their degree programs. "This means that labs have to be fully accessible, [and] field training sites and internship workplaces need to be reimagined," she noted, which requires working in conjunction with employers.

Second, researchers need to build on the foundation of knowledge about how ableism can be disrupted, and workplaces made to be inclusive. "I can't stress this enough, especially coming from NSF, that that research base is so critically important," she added. Third, and most importantly, Marrongelle said, we need to create communities that value and respect the contributions, experiences, and perspectives of people with disabilities, and embrace those contributions in STEM: "It is that culture change that is going to take the longest but is the most important."

Swenor asked McNutt to describe the gap between the impression that people with disabilities cannot succeed in STEM versus the reality that they do. McNutt began by asking the audience, "Who here has never heard of Stephen Hawking?" No hands went up. "We don't have enough counterparts for Hawking," across all the fields of science, she said. Years ago, as head of the organization that operated the U.S. oceanographic research fleet, she was involved in a study to understand what it would take to make research ships accessible for people with disabilities. She realized being unable to name similarly famous oceanographers with disabilities was an illustrative problem. "We will never be able to list them if we don't make our field accessible to those with disabilities," she said. "We have to start there." Scientific fields are not showing the full range of possibilities for what science looks like, McNutt added. "If our advertisements for people in the geosciences are people in lederhosen with hardhats scaling cliffs in order to get geologic samples ... that is certainly not going to look like a real inviting place. You could be a geoscientist and be working on the next generation of climate models and you never have to scale a cliff," she said.

Swenor asked Marrongelle what ideas or advice she had for STEM leaders for disrupting ableism. "There is not going to be a one-size-fits-all solution and so we need to recognize that and celebrate that," Marrongelle said. Instead, leaders must support and test a broad range of approaches. "I think especially for STEM leaders we need to ensure that once we have done that experimentation ... we need to prioritize the sustained growth and lasting change of what is needed," she added. Leaders need to say this is important and prioritize it through budget or policies, she said.

Disrupting ableism in STEM creates positive outcomes for a variety of people, McNutt said. "There are too many brilliant minds that are either being unemployed or underemployed because we haven't made the accommodations to actually take advantage of their skill sets and their enthusiasm and their brilliance in the science field." But such changes have broader implications, she noted. A friend of hers used widely available broadband to organize an oceanographic cruise with scientific parties both on the ship and on shore. Those ashore, including those with disabilities, got real-time data and video from underwater vehicles to do data processing. Not only were they not seasick and needed less downtime to do their work, but the data were also being processed in real time and informed research decisions, guiding the expedition to take the most advantage of the time at sea.

"All sorts of people that we might not necessarily view as having conventional disabilities were able to be included in it," McNutt said. "I'm thinking of a mother at home with a young baby: she can't leave to go for 1 month out to sea, but she can certainly log in for a number of hours every day and lend her expertise." The bottom line, McNutt said, is expanding the diversity in the workforce. "It is the same argument we make for including women and including minorities, but it is also for disabled people. They bring a unique perspective that we need to take advantage of."

#### THE INTERSECTIONS OF DISABILITY, EQUITY, AND STEM

Mona Minkara, planning committee member and head of the Computational Modeling for BioInterface Engineering, or COMBINE, Lab in the Department of Bioengineering at Northeastern University, moderated a panel with three scientists to discuss the intersections of disability, equity, and STEM. She encouraged the panel to "really push our limits and talk about things that we usually are too uncomfortable to talk about."

#### Lived Experience

Throughout her schooling, Anjali Forber-Pratt, director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), was "constantly faced" not only with physical inaccessibility, in terms of accessing spaces, but also attitudinal inaccessibility. She faced assumptions that she would not go to college or was not interested in science because of her disability, and ultimately took her school district to court over not being allowed to sign up for a specific science class. And as she entered higher education and became a researcher, she found there was a lack of disability representation: very few professors and researchers that looked like her. "It really drove me down this pathway of studying disability identity development, and how is it that individuals can make meaning and be proud of the disability," she said.

Cassandra McCall, professor of engineering education at Utah State University, was diagnosed with Stargardt disease, which is causing her to slowly lose her central vision, when she was in a doctoral program. She was experiencing both the transition of moving into engineering education as well as how to navigate the world and accept things like not being able to drive anymore. "I was pretty open about it in terms of working with my dissertation committee," she said. In her postdoc career, she has worked with students with disabilities in civil engineering, "trying to understand more about their experiences and what we do as engineering faculty to perpetuate or stigmatize disability identity and engineering identity."

Wanda Díaz-Merced, an astronomer at the European Gravitational Observatory, said that as she transitioned through different levels of her career, as a Blind person, she did not have access to the same amount and quality of information. "At every single transition from one aspect of performance to the other, we would start with a disadvantage," Díaz-Merced said. She likened it to transferring schools to another country, where you began getting lower grades, not because you were suddenly a worse student, but because of a language barrier. This "imposed disadvantage" was very hard for others to perceive, she said.

"If the playing field is equalized, then we will be able to participate equally, and we will be able to achieve and progress equally," she said. "No one will start with a disadvantage." What made a difference in her journey was seeking scientific evidence for how audio could be useful for astrophysical research. "With simple, very well-designed experiments, all other

opportunities opened up, not only to better more detailed discoveries in science but also ... to bring all performance styles to do science."

Minkara asked how disability has informed Forber-Pratt's career and the field at large. Forber-Pratt said disability is such an important part of who she is and drove the types of research questions she wanted to study as a scientist. That continues as the leader of NIDILRR, to make sure the entire research enterprise and all steps of the research process are supportive of people with disabilities—not only investigators but also project officers, peer reviewers, and participants.

Disability identity has both internal and external components, Forber-Pratt said, including how you talk about that identity to others, and when you disclose. There are layers of complication based on the type of disability you may have, if you have multiple disabilities or if you acquire them later, she added. "How you find and build that sense of community and solidarity with that broader disability community for me and for many individuals … becomes a protective factor when you encounter elements of ableism," she said. Now that she is in the position of being able to award grants and form research policy, Forber-Pratt said, all of these elements are "helping to guide the decisions that I make every single day," and foster conversations with federal colleagues and grantees.

Minkara noted that Forber-Pratt had used the word *ableism* and asked the panel how each of them defined that term. Forber-Pratt said ableism was "inequities, prejudices, and discrimination that we experience and that occur because of our disability" but was also the systemic elements. In this way it is similar with other *isms*, she added, in that it was not just one singular barrier or singular incident. "I was being counseled out of considering a field in research and in science; it was the compounding element of hearing time and time again from multiple people of authority ... that then followed me throughout my entire career," Forber-Pratt said.

McCall agreed and said it is difficult to make a cultural shift when many people do not experience or are not aware of the barriers. "I have a colleague who talks to me about it as being a fish in a fishbowl. How do you tell a fish that they are living in water because that is all they have known?" These conversations are really bringing things to the forefront "that have been embedded in our society and in our cultures for so long," she added.

#### What Does It Mean to Have Equity in STEM?

"I will go for equity, and I do not go for equal," Díaz-Merced said. "When it is equal, I may not have the things that may feed my context in order for me to perform." Equity is about being able to "decide freely" and "not rely on premade choices made for us," she said. STEM fields also need to stop "patching things that have been broken for a long while" and instead invest money to rebuild. Addressing people's needs to do their science will improve science at large, she added. "If someone is performing outside of the limited spectrum, the potential for science increases exponentially when the limitations are removed." She gave the example of how the development of radio astronomy—moving beyond what scientists could see only with their eyes—wholly changed the field. "It propelled development of space science because it was not limited to how far the eye can see." STEM fields now have "an investment to make ... to rebuild the scaffolding in the way we are performing in science, change the economic models, and change the metrics of productivity," she said.

"I have some colleagues who are very concerned about maintaining equality in the classroom, often described as fairness," McCall said. "Things like accommodations or extending testing times—they are really uncomfortable with." But these are tools that help people "demonstrate their knowledge and their capabilities," she added. In her own teaching, she has tried to develop a flexible system for students, not only in response to COVID-19 but to make class accessible for people managing differences and short-term disabilities. STEM fields "don't have to continue the trajectory we have been on" and instead can develop practices such as making field experiments more accessible. She emphasized that equality and equity are not the same.

Equity is also about "meeting communities where they are at," Forber-Pratt said, and that includes allocating resources to make up for historical oppression and systematic ableism. All of these conversations, she added, are about working toward justice, "toward the dream where we can exist and interact in society and in our professional jobs, in the world free from barriers or from oppression." Unfortunately, ableism prevails within the disability community itself, she said. Certain disabled voices, including those with traditional disabilities, get privileged over others. "We tend to place more value on that input, as opposed to an individual, say, for example, who might be nonspeaking or have intellectual disability or any combination thereof." Breaking down those hierarchies is required to fully realize equity, Forber-Pratt said.

#### **Taking Action**

Minkara asked the panelists what policies they would like to see change to move toward equity in STEM. McCall said that she is thinking more about how students can be supported to consider opportunities in STEM and how they can pursue them. "Engineers are considered to be people who fix things," she said, and disabled students have spoken with her about the tension between their disability identity and their engineering identity—they cannot "fix" their disability. She is also working with vocational rehabilitation counselors at Utah State University to get more students with disabilities into STEM, as well as getting more faculty support, especially for those who are not already interested in disability as a research area. "We are trying to figure out how do we get these communication channels open and streamlined to where faculty are also on the ground making these decisions and helping to create more inclusive classrooms," she said.

Díaz-Merced said her action began with evidence that more tools were needed for scientific research. "When we did the first experiments that showed professional astrophysicists at Harvard, [that] sound increases their sensitivity to events in the data that *by their nature* are blind to the eye, that was really, really shocking . . . but [it] also was a turning point," she said. She could no longer be told that such tools were solely for education and outreach but could be used for scientific research and bringing more people into the pipeline of making scientific contributions.

"We need a policy to put in place the things needed for the current scientific economy to transition to multisensory practices," she said, along with policies that strengthen international frameworks to support affected individuals. Whether through an office, mandate, or treaty, Díaz-Merced said, policies must prevent and correct inaccessibility, emphasize the role of people with disabilities in producing science, validate multisensorial practices, and support career transitions for those who acquire disabilities later in life. "I urge a rapid transition to methods that are not reliant on current methods of practice, and especially do not rely on current web accessibility guidelines," she said. Minkara agreed, as a Blind person, that she would love to see all digital content become fully accessible.

The Biden-Harris administration has a set of executive orders for advancing equity that explicitly names disability, Forber-Pratt said. In her own work at NIDILRR, it is important to gather data to identify how they are fulfilling these executive orders—including grants, principal investigators, fellowships, and capacity building. "We believe wholeheartedly that

people with disabilities should be on our peer-reviewed panels, but we weren't actually systematically collecting that data," she said. Forber-Pratt recently went through a process to assess NIDILRR's own internal peer review process and develop and administer a survey to their peer reviewers. "We actually will be able ... to really make sure that we are practicing what we preach."

#### What Can Others Do?

At the end of the panel, the experts answered a series of questions from the audience about what people with ability privilege can do to redress or repair damage done by STEM institutions to people with disabilities, how to improve the language and conversations their colleagues are having around disability, and how to build community.

Build on that awareness of privilege by making sure you are inviting people with disabilities into conversations and decision rooms, Forber-Pratt counseled. One way is to use invitations, whether to serve on a committee or speak on a panel, to suggest bringing someone else along or having them go in your place—and saying why.

Díaz-Merced said scientific institutions needed to address the harm their past policies and hiring practices had done to disabled people, and cited NASA as an agency that had begun to address this publicly. McCall suggested a book titled *Keywords for Disability Studies* (Adams et al., 2015), which explains common concepts for those who are not experts to understand the historical and political implications of disability. She also suggested getting to really know people, so that you understand their disability is only one aspect of who they are. Minkara added that allies must really listen to people with disabilities when they explain how they identify. She has had multiple instances of people being "horrified" when she says she is Blind. "But I *am* Blind," she said.

Part of building a community, Forber-Pratt said, is being willing to engage in the questions of how the community and the physical space can be more accessible and supportive for all. When she was leading a research lab, they had a conversation about everyone's access needs whether they identified as having a disability or not, and allowed for changes. "If you are not used to what accommodations you might need in order to be successful at a specific task, it will be a little bit of trial and error. We just had that be a standing agenda item in our lab at meetings, checking in about access."

Allies can respond to discrimination and prejudice by asking the person with a disability how they can best respond to a bad situation, Forber-Pratt said. "Say, Hey, I'm willing to help. How could we figure this out together?" But allies can also say something if they notice an ableist practice in general, "when you see a car that is blocking the ramp and when you see materials aren't available in accessible formats," she said.

Díaz-Merced agreed, adding that many times disabled people do not say things because they fear the response. "Having a voice of support may make a humongous difference and it may make us feel, for the first time, safe in our professional environment."

As a takeaway from the conversation, Forber-Pratt said achieving equity is doable, but "it takes every single one of our expertise," regardless of disability or job role. "We literally need all of us from our own vantage points—whether you're in a university or in federal government or whether you are trying to get grants—we need every single one of those perspectives in order to bring about change," she said. Small actions add up, McCall added, and communicating the actions and strategies you are taking widely has an even bigger effect. Díaz-Merced agreed that having difficult conversations was healthy, "but I think we are at a stage in which we have to take concrete actions."

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## Centering Disability and Identifying Equity

#### DESCRIBING DISABILITY AND ABLEISM

As part of the leadership summit, Jacquelyn Chini, professor of physics and undergraduate program associate director at the University of Central Florida, presented an overview of her forthcoming paper<sup>1</sup> on describing disability, including different ways of defining and understanding disability and discrimination against disabled people.

#### Impairment and Disability

Chini began with a definition from Disabled Peoples' International (DPI)<sup>2</sup> that specifically splits impairment and disability. *Impairment* is a functional limitation within the individual caused by physical, mental, or sensory impairment. *Disability* "is something extra on top of impairment," Chini said, sharing the definition from DPI: "The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical or social barriers."

Chini defines ableism as a bias, possibly subconscious, in favor of able-bodied and able-minded people. "With this comes the assumption, again possibly unexamined, that nondisabled people are inherently superior

<sup>&</sup>lt;sup>1</sup> Chini, 2023, *Describing Disability: Language and Models* (https://nap.nationalacademies.org/resource/27245).

<sup>&</sup>lt;sup>2</sup> See http://dpi.org/.

to disabled people." Society is steeped in ableism, Chini said, "so of course we will all have ableist ideas that pop into our minds." She shared two quotes with different perspectives on ableism, first from Gregor Wolbring (2008), who wrote that ableism "reflects the sentiment of certain social groups and social structures that value and promote certain abilities, for example, productivity and competitiveness, over others, such as empathy, compassion and kindness." And in *Academic Ableism: Disability and Higher Education*, Dolmage (2017) says academia "powerfully mandates able-bodiedness and able-mindedness, as well as other forms of social and communicative hypermobility," a demand that reflects ableism. "In fact, few cultural institutions do a better or more comprehensive job of promoting ableism." These are "pretty strong claims that we in the academies are situated in ableism," she concluded.

#### Ableism versus Disableism<sup>3</sup>

Chini then contrasted disableism—prejudice against disabled people—with ableism—a prejudice in favor of able-bodied people. "I think sometimes when we have this knee-jerk reaction to say I'm not ableist, we might be more thinking about something like disableism," Chini said, sharing another Dolmage quote: "Disableism says there could be nothing worse than being disabled and treats disabled people unfairly as a result of these values. Ableism on the other hand . . . positively values able-bodiedness. In fact, ableism makes able-bodiedness and mindedness compulsory" (Dolmage, 2017).

Chini said she finds it useful to separate these ideas out, because while the active discrimination of disableism happens in science, technology, engineering, and mathematics (STEM), ableism without disableism still has consequences. "Disabled people may become hidden, where we are just not planning for them to be in these spaces," she said, such as a colloquium speaker refusing to use a microphone, assuming there is no one who needs voice amplification or has technology working with the microphone system; purchasing software that is incompatible with screen readers to be used in a class; or requiring specific work hours instead of flexibility for medical appointments or other bodily needs.

<sup>&</sup>lt;sup>3</sup> There are two spelling conventions "disableism" and "disablism" 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."

Anti-ableism, Chini said, "is a new framework, which involves recognizing able-privilege and using strategies, theories, actions, and practices to actively dismantle it." She shared a quote from two scholars of that new framework, Lalvani and Bacon, working in early childhood education: "Disrupting ableism can only be achieved if teachers position disabilities 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" (Lalvani and Bacon, 2019). A second set of scholars, writing in a postsecondary education context, say "anti-ableism is a systemic approach to both promoting the belonging of disabled students and preventing the exclusion and marginalization of disabled students" (Nieminen and Pesonen, 2022). The aim, Nieminen and Pesonen say, to disrupt the ideals of normalcy and productivity is often underlined in teaching practices. Anti-ableism is looking at both disableism and ableism, Chini said, working to actively include disabled students, to value disabled people, and to work to dismantle ableism.

# Talking about Disability and Assumptions in STEM

When talking about disability, it is important to "say the word," Chini said. "There is no uniform consensus on anything, but we all need to get comfortable saying the word *disability*" (Andrews et al., 2019). There is less consensus on whether to use person-first or identity-first when talking about people, she added, but she suggested following what the person you are talking about or talking to prefers (Sharif et al., 2022). She will discuss this element deeper in the forthcoming paper.

"What is really important in the STEM community is to learn about and avoid harmful language," Chini said, adding that lots of terms we use in our everyday life are based on disableism (Brown, 2022). There are many assumptions in the STEM community around disability, she said, but one of them is the idea that the laws for combatting discrimination and creating accessible environments makes it easy for a disabled person to get accommodations. "Many people here can speak to that that is not the case," she said. She shared a quote from two lawyers writing about Canadian postsecondary education that describes how laws fail to create a "positive obligation" to include students. Rather, "the onus of asserting rights or identifying code breaches rests with students.... As a result, the students who lack the will, endurance, means, or ability to lodge a formal complaint may continue to be victims of discrimination" (Prema and Dhand, 2019). "We are putting

extra work onto the folks who need access to prove their case for getting that access," she added.

#### Models of Disability

The two most common models of disability are the medical model and the social model, Chini said: "These models differ in where they situate disability and how they define disability as well as where the burden for change lies." The medical model situates disability within the person, directly arising from the impairment, and it is often rooted in notions of treatment and care. One positive that comes out of the medical model is medical and technological advances that may lead to improvement in disabled people's lives, she said. In the social model, disability is situated in social structures and the environment—the disabling results from inadequate and inaccessible environmental conditions. Access is provided by removing social and structural barriers, Chini said, and a positive from this model is a positive integration of disability within one's identity.

But many policies, stances, and interactions are best described by multiple models of disability, Chini said. The forthcoming paper presents a cluster model for thinking about disability that uses a three-dimensional framework. The medical and the social models are at opposite ends of the "cause of disability" dimension. The effect dimension includes a spectrum of tragedy versus affirmative models of disability. At one end are models that frame disability tragically, "that disability has only negative impacts on a person's life and well-being," Chini said, and on the other end are affirmative models "that make space for the positive impacts that disability can have on a person's life and well-being." A third dimension are two models that address the dichotomy of ability and disability. Under the minority model, Chini explained, certain characteristics are shared by people with a disability and only people who have those characteristics are considered disabled. "On the other end is the universal model, which considers that all people at some point will acquire a disability, so they're not going to make a distinction between disabled and nondisabled people," she said.

Chini gave examples about how this multidimensional model shows up in different ways, including antidiscrimination policies, which reflects social and minority models "because you have to meet a certain definition of disability in order to access protection" and universal design, which can be described by the social and universal models "because it's taken into account the full range of human variation."

There are many other models of disability, including critical disability theory, crip studies, critical realism, Deaf epistemologies, among others, that the forthcoming paper will discuss, Chini said. These models highlight "the importance of intersectionality of disability with other aspects of identity."

#### Statistics in STEM

Chini also reported on statistics of people with disabilities in STEM. While there are regular updates on these data through the U.S. National Science Foundation (NSF) and other surveys, gaps remain, she said, including bachelor's degrees earned by students with disabilities, and graduate degree program enrollment. Overall, representation of people with disabilities in the STEM workforce is lower than the wider labor force and total population overall, Chini said, but STEM careers show similar median wages for disabled people compared to nondisabled people. "Very few folks who are funded by the National Institutes of Health [NIH] and NSF identified as having a disability," Chini added, about 2 percent and 1 percent, respectively.<sup>4</sup>

Among postsecondary students, self-reporting disability has grown in the past decade. "From 2011 to 2015, the percentage of students who identified with a disability doubled," Chini said. The increase seems to be from certain types of disabilities being reported, specifically an uptick in those with attention deficit disorder, mental illness, and depression.<sup>5</sup>

Several possible next steps came out of a discussion of the paper, Chini said, including increased support for disability disclosure, adopting disability status metrics across wider datasets such as the Integrated Postsecondary Education Data System, or IPEDS, and the Graduate Students and Postdoctorates in Science and Engineering. There was also a call for qualitative data about disabled people's experience in STEM, "so that we are not just counting people ... but how we are improving or not improving," Chini said.

<sup>&</sup>lt;sup>4</sup> For more information, see https://ncses.nsf.gov/pubs/nsf23315/. See also Swenor and Rizzo, 2022.

<sup>&</sup>lt;sup>5</sup> See https://nces.ed.gov/.

#### REFLECTIONS

Several barriers contribute to the lack of people with disabilities in STEM, said Vivian Cheung, professor of pediatric research at the University of Michigan School of Medicine. One of them is how hard it is to get accommodations. Cheung is a tenured full professor, a member of the National Academy of Medicine, a board member of various nonprofits, and an active researcher who runs a lab—"by many standards, I succeeded in climbing this career ladder …but I also have many scars that I have acquired in my professional journey." At a previous position she was denied access to a temporary assistant after suffering a spinal cord injury, then was asked to retire after showing up with a wheelchair and then a service dog. "I was probably deemed *too* disabled," she said. "My story is not unique, and I think such a story is not in our rearview mirror yet," she said, and added that for there to be more disabled people in STEM, leaders must not tolerate ableism or discrimination of any form.

Another element is clearing the pathways to STEM careers, Cheung said. Medical students have had to both show documentation and write essays to explain why they need accommodations and "as a doctor, I just do not understand that," Cheung said. "If I say my patient is Blind, the university should not question that, or ask ... are you sure you need accommodations? Instead, they should ask what they can do to help the student to succeed." These barriers mean that by the time a student has progressed from college to getting an M.D. or Ph.D., they already know that the system is against them, Cheung said, and they will struggle to have a seat at the STEM table. The problem, she added, is inaction and indifference of many people—bystanders need to speak up.

Jae Kennedy, professor of community and behavioral health at Washington State University, pointed out that in the statistics Chini shared, mental health and depression were the largest types of disability. This means the issue of disclosure is critical, Kennedy said. Having a work culture where it is safe and accepted to acknowledge differences, different needs, and disability is an active decision, and the National Academies, NSF, and NIH "have to take the lead on this." Along with their external stakeholders, the federal research enterprise needs to lead on destigmatizing and encouraging disclosure, even when accommodation is not needed or there is no identified discrimination. "It just needs to be normalized," he said.

The work on accessibility and inclusion in STEM is as global of an enterprise as STEM itself, said Mahadeo Sukhai, vice president of research

and international affairs and chief accessibility officer of the Canadian National Institute for the Blind. "Half of our postdocs come from outside the United States," he said. "We need to recognize that scientists flow all over the planet and we collaborate with people all over the planet," and that needs to be part of the accessibility conversation.

What makes up essential requirements in STEM also needs to be part of the conversation, Sukhai said. STEM values capability, but that is not the same as valuing ability. "In science, we say there are essential requirements ... and you have to do them in a specific way. You can't receive accessibility support; therefore, we can't work with you as a person with a disability," he said. "You need to be able to ask the question, If I do them in a different way, does it actually make a difference?" STEM fields are rigid in their thinking about how people are supposed to learn and do their science, like requiring someone to be able to hold a pipette to do a chemistry experiment, Sukhai added. The STEM disciplines are not very good, collectively, about trying to identify "what is it we actually want to learn and what is [it] that we actually want to do," he said. It is a core challenge in the conversation around accessibility support and inclusion in STEM.

# Myths of Ableism

Panel moderator Michele Cooke, a professor of geosciences at the University of Massachusetts Amherst, asked Chini and other panelists to discuss some of the myths about disability that feed ableism, starting with the myth that the Americans with Disabilities Act (ADA)<sup>6</sup> "solved everything."

After the laughter from the crowd ebbed, Sukhai noted that the idea of "accommodations" in the ADA had been misconstrued to be associated with something more like another meaning of that word: a hotel stay—not a requirement to do a job. "We really need to think about what is the accessibility support I need to do my job, and what is the accessibility support I need to learn," he said. "As opposed to, I need help, which then begs the question, well why do you really need help? What are you doing here if you need help."

Disclosure is fraught for people with hidden disabilities, Kennedy said. Those with invisible disabilities must prove they need help; that is, explain the help they need and justify it. "That is very difficult, particularly for

 $<sup>^6</sup>$  42 USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

young scientists and scientists in a very competitive market for jobs and grants," he said. If disclosure could be decoupled from that request, from accommodation, that might solve some of these problems, he added.

A different take on the ADA myth is that it assumes the person knows they have an access need, Chini said. "The ways that ableism shapes how we do science ... impacts kids and people to think that they don't belong in what we are doing and they can't ask for accommodation," she said. Cheung echoed Chini's comment and said, especially for young scientists, barriers needed to be lowered. NSF, NIH, and other organizations can help to make it possible for students to ask for accessibility "without having to be retraumatized over and over again," she said.

The second myth is that if people are not asking for adjustments to the workplace or for themselves, the workplace must already be fully accessible and not need any changes, Cooke said. What can people do in our various roles to make disclosure safer? she asked. Acknowledging disclosure is a risky action, and not without consequences, Kennedy said, and institutions need to support people who do so. Leaders of all kinds can role model this, but particularly, senior leaders in academia and the federal research enterprise can disclose their own disabilities. "We need to have people that are braver than me saying this earlier and more often in their careers," he said.

One of the useful things in learning about different models of disability is helping us examine how we think through things, Chini said. Raising up Stephen Hawking as the example of a disabled person in physics not only has gendered and racial significance but implications for disabled people at large. "We need to be careful that we're not falling into this tragedy model of disability, of saying you have to be this exceptional case in order to overcome your disability and be in the space," she said.

Sukhai said that leadership in organizations must move the conversation away from an "ask" mentality and, instead, think about ways that the workplace, the lab environment, or the training environment can be inclusive from the start. "Sometimes it could be as simple as that, to say: I invite the conversation, but even if you don't feel comfortable, we can still do things to make this place inclusive."

# Leadership that Challenges Ableism

From the virtual audience, Kate Mittendorf, a senior staff scientist at Vanderbilt-Ingram Cancer Center, said STEM needs leaders who will not tolerate ableism, and asked the panel: What would that look like, especially when reporting discrimination or ableism results in retaliation?

Hiring committees need to ask point-blank during the hiring process, What would you do if someone brings a complaint or report to you?—because it is not uncommon, Cheung said. "When someone never reports such events or describes how they deal with it, we sort of know they are failing to do so." Leaders need to be accountable to the board when they fail to account for discrimination and retaliation. Ableism can rear its head in ugly ways, but more common microaggressions can be just as damaging, Sukhai added, and leaders can respond to that. An anti-ableist leader is the vice provost who moved a meeting location because the lighting was so poor, or the CEO who said if Sukhai could not read the documents, they would not read them and would refuse to discuss them until there was an accessible version.

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# Cultivating Accessible Educational Pathways and Spaces

# CHANGING MINDSETS: SYSTEMS, PROGRAMS, AND POLICIES

Emily Ackerman, a postdoctoral researcher in the Lahav Lab at Harvard Medical School, began the workshop on educational pathways and spaces with a panel on changing mindsets in systems, policies, and programs in higher education. She began by asking the panelists about systemic barriers to full participation of people with disabilities in science, technology, engineering, and mathematics (STEM) education.

One barrier is the lack of representation, said Lisa Meeks, clinical associate professor at the University of Michigan and executive director of the Docs With Disabilities Initiative. We send messages, covertly and overtly, through society about what people can and cannot do, she said, and "when you don't have counter-stories, you don't have opportunities to see yourself going into those scientific roles," especially for women, people with disabilities, people of color, and the LGBTQIA+1 population. Stories and mentorship are needed for people to grasp onto and say they can go down this career path, Meeks said.

Attitudinal barriers manifest into direct barriers, said Yvette E. Pearson, vice president of Diversity, Equity, and Inclusion at the University of Texas at Dallas. As a program officer at the U.S. National Science Foundation

<sup>&</sup>lt;sup>1</sup> LGBTQIA+ refers to individuals who are lesbian, gay, bisexual, transgender, queer/questioning, intersex, ally/asexual, and other sexual and gender identities.

(NSF) several years ago, she spoke to a group of leaders from state schools for the deaf and blind who were interested in a collaboration. They were interested in bringing together education and workforce partners to help their students advance into STEM education and career paths. But the workforce partner missed a half-day of discussion, and one of the first things they said when they showed up was: "Well, I just don't think we have any jobs they can do." Starting with that mindset sets up systemic barriers that keep people out, Pearson said.

### Disability Resource Providers and the "Real World"

In Pearson's own experience in academia—as well as in the literature—what keeps showing up is misconceptions about accommodations for students with disabilities, particularly students who have unseen disabilities. There is a widespread sentiment that somehow providing accommodations is unfair to students without disabilities or doing so somehow does not prepare students for "the real world," she said, and this ignorance around disability leads to a lot of barriers.

A related barrier is the lack of standardized education for disability resource providers (DRPs) on campuses to understand STEM fields, Meeks said. "They may be able to understand accommodations in an English classroom, but that will not translate to a biology or chemistry or engineering lab," she said. DRPs are critical because they work with both students and faculty, but they are underpaid, underappreciated, and underfunded, Meeks said, and they need to be supported more clearly and be offered more professional development opportunities. "The real world is almost always more flexible than any educational program," Meeks added. On both her and Pearson's podcasts, they try to elevate stories of people who are disabled in STEM fields to "dismantle the belief systems and attitudinal barriers."

As a wheelchair user with very limited use of one side of her body, Pearson said being in the world every day is a problem-solving exercise, and it is critical that that perspective has the opportunity to be added to STEM conversations. Within the past year, she is proud that her university has been able to bring accessibility under the umbrella of diversity, equity, and inclusion. As a result, both student and employee accessibility are managed in one place, and they can begin to move beyond being a caseload management organization to a true resource center for the broader campus community, she said.

## **Institutional Changes**

Ackerman agreed that this fits with her experience of navigating educational spaces as a student. "Most disabled people wake up every day [and] find they live in a system that is not made for them. The educational institutions that we know and love were not designed to hold us, and so we go throughout our days fighting these barriers," she said. Ackerman then asked the panel what changes are needed at the institutional level.

"We need to get rid of or dismantle the exchange system we have set up where you have to tell me you are disabled and you have to prove you are disabled, and then I might do something to modify the system," Meeks said. Her own experience with a degenerative autoimmune disorder has shown her that people make assumptions about her disability and access needs, which are reflected in the conversations they have about her disability. Instead, educational spaces can acknowledge that many people coming to them may have a disability and start looking at universal design as a mechanism for building inclusive environments proactively, "instead of always being in this reaction mindset," she added. Institutional messaging also needs to acknowledge there are disabled scientists and disabled engineers, she said.

Universal and accessible design offer "huge opportunities" in the context of curriculum and the way we educate students, Pearson said. She and her partner, Ann Gulley of Auburn University, led a team for an NSF-funded study to test and study a novel way of teaching and assessing mathematics that was developed when Gulley was at Auburn Montgomery to help a student who was blind and whose mobility limitations meant that he could not use traditional braille.<sup>2</sup> "Some might say a reasonable accommodation would be to waive the math requirements, but then what is your degree worth?" Pearson said.

The process of developing this learning approach,<sup>3</sup> Process Driven Math (PDM), was very user-centered and user-driven, Pearson said, and was later adapted for sighted learners. The team saw all sorts of benefits for students with and without disabilities. As an engineering educator, she also cited a change in the field's accreditation criteria in 2019 that "opened up a world of possibilities for us to think differently about how we educate more inclusively and more equitably" as well as educate future engineers to be more inclusive

 $<sup>^2</sup>$  For more information, see https://www.nsf.gov/awardsearch/showAward?AWD\_ID=1726869&HistoricalAwards=false.

 $<sup>^{3}</sup>$  This process was developed by Gulley, Logan Prickett (the student-user), and Jordan Price.

in their own practice, being able to receive information from an audience who may have a range of disabilities, and integrate that into their work. Moments when solutions like these are "baked into the design" of the institutions are rare, Ackerman noted, but are really meaningful to the student.

#### **Sharing Practices**

One of the pivotal reasons for creating the Docs With Disabilities Initiative and other groups has been the siloing of people and solutions, Meeks said. People would devise a solution for one institution or one learner but would not make a universal design based on that experience, nor share it with the world. "We need to find a way to operationalize this as just the new normal," she said. "Let's embed this into the way we teach or assess so that that is already in place and we will build on this each time." This would also remove an attitudinal barrier, Meeks added. When you are faced with the evidence that this is no big deal, that this has been done countless times across institutions—avoiding the fear of the unknown that drives so much of ableism. Making solutions part of the new normal also helps people with disabilities be valued and fully integrated in the institutions. "You can create access and still make people feel excluded," she said.

# Wider Changes

Meeks said she loves accurate media portrayals of disabled people that model integration and access. People sharing their lived experience and disclosing is powerful, but she would like to see more effort in storytelling for younger students. "To have an impact we need to start at elementary school," she said. "I think we need to send messages to children as they develop, they can be anything they want to be regardless of disability status.... It is part of being human, and we need to not make it super inspirational or villainize it."

Stories of lived experience of people with disabilities help parents see real possibility too, Pearson said. She also wants as many institutions as possible to move beyond a compliance viewpoint, where "checking a box" when complying with the Americans with Disabilities Act<sup>4</sup> or state and local laws can still mean things are inaccessible and do not lead to feelings of belong-

<sup>&</sup>lt;sup>4</sup> 42 USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

ing. Having people with different types of disabilities engaged from the very beginning is key, "because we can bring so many different perspectives, we can help illuminate ... what the possibilities are," Pearson said.

# DISABILITY-FRIENDLY SPACES IN HIGHER EDUCATION AND UNIVERSAL DESIGN FOR LEARNING

Sam Catherine Johnston and Luis Pérez, both from the postsecondary and workforce development office at CAST,<sup>5</sup> presented their forthcoming commissioned paper,<sup>6</sup> on creating disability-friendly spaces in higher education and universal design for learning. CAST's vision is educational spaces where "every learner can have engaging opportunities to access education training environments that are designed with their needs and preferences in mind," Johnston said. Creating greater equity in education and training systems will create a broader range of people informing the STEM workforce, including delivery of STEM-related services and care, she added.

# Social Construction of Disadvantage

While the paper covers how universal design for learning can create more inclusive practices, their bigger "North Star" is to "address the fact that for many, many decades we've ... rewarded a narrow definition of intelligence and learning in our schools in a way that excludes people with disability as well as many other groups," who do not fit into "one-size-fits-all" systems, Johnston said. From early education onward, the expectation is that all students in a very narrow age range will accomplish the same things in the same ways, she said, but that is not aligned with variability in human learning and contributes to the elimination of differences. Remediating or excluding these variabilities in the education system is sometimes not connected with functional issues, but instead, with stereotypes, she added.

Universal design for learning (UDL) functions in the opposite way, centering difference and human variability as an asset. "UDL is about starting in the margins," Johnston said, understanding for whom systems are not effective and then moving toward the middle. "So what is essential for some, benefits many. We really see the margins as the source of innovation."

<sup>&</sup>lt;sup>5</sup> See https://www.cast.org/.

<sup>&</sup>lt;sup>6</sup> Pérez and Johnston, 2023, Creating Disability Friendly and Inclusive Accessible Spaces in Higher Education (https://nap.nationalacademies.org/resource/27245).

Pérez added that a narrow definition of intelligence also excludes collective intelligence: the way we learn in a social environment and the way we interact with technology to learn. He delved further into the idea of social construction of disadvantage in that for a long time left-handedness was constructed as negative in educational spaces, even punished with physical violence. But a change—the ballpoint pen—deconstructed the disadvantage of being left-handed when writing, Pérez said, and identified the flaw was in the tool, not in the person themself. The forthcoming Pérez and Johnston paper argues that if someone is not learning in a STEM course, look at the learning barriers; do not blame the student. "I think the other lesson there is that remediation so often doesn't work," Pérez said. "You're asking someone not to do what's natural, not to lean into their own intelligence, their own ways of being in the world." There is hope for change in the left-handedness example, he said.

#### Universal Design for Learning Framework

First defined in the Higher Education Opportunity Act (2008),<sup>7</sup> UDL is an evidence-based framework that draws from the learning sciences and instructional methods to design for the widest range of learners from the outset, Johnston said. With UDL, "we create flexible, customizable, and accessible learning environments and experiences," she said, and it centers variability.

UDL comprises three major principles based in three types of learning networks, she explained. First are the affective networks in our brain, that is, why someone pays attention in the first place. "We need to provide multiple means of engagement so that we can ensure students who are motivated through different ways ... have entry points into and through our environment," she said. Second are the recognition networks, the "what" of learning. UDL supports multiple means of presenting information and ways of accessing and comprehending the learning. "We have more than one way of presenting content here [at the workshop]," she noted. Finally, there are strategic networks—the "how" of learning. UDL provides multiple means of action and expression of that learning. "This is so critical in STEM," Johnston said. "We want to make sure in our strategic networks—the frontal part of our brain—that we allow for different ways to build skill development and to express what we understand so [that] we can continue to build skills and knowledge in labs and fieldwork."

<sup>&</sup>lt;sup>7</sup> P.L. 110–315, August 14, 2008, available at https://www.congress.gov/110/plaws/publ315/PLAW-110publ315.pdf.

#### Accessibility is Foundational

Both ableism and disableism<sup>8</sup> are forces that work to exclude learners, Pérez said. UDL needs to consider the design of the environment, but we also need to look at its assumptions, he said. "We have to change the mind-set before we go into specific design practices, because otherwise what we are doing is kind of patching the cracks in the foundation of a building that is not standing on solid ground." One of the key concepts is "accessibility is foundational," or what is essential to some is helpful for all, Pérez said, using the curb-cut effect as an example of this in practice. Flexible learning practices also benefit people going back to school, people who need literacy support and working memory support, as well as multilingual learners.

A focus on UDL also does not mean that accommodations can be excluded from consideration. Instead, they can be partners in inclusion, Pérez said, adding that taking a UDL-first approach addresses the limitations of solely focusing on accommodations. Many of these limitations are applicable in STEM, where much of learning does not follow predictable classroom structure required for most accommodations. "They don't work as well when a lot of the work is independent or research work and you need to avail yourself of lab spaces and research facilities," Pérez explained. Accommodations also place the burden to change on the student, rather than on the curriculum, he added. A common example of UDL and accommodations working together is using both captions, which benefits a range of different people, and American Sign Language (ASL) interpreters, which may be more effective for those whose first language is ASL.

# CAST's Suggestions for Lab-Based Learning

Much has been written about UDL in the classroom, including by CAST itself, so for the paper, Johnston and Pérez wanted to focus on steps to bringing accessibility to labs and fieldwork, Pérez said. Their suggestions include the following:

Incorporating universal design principles into the design of the lab space

<sup>&</sup>lt;sup>8</sup> There are two spelling conventions "disableism" and "disablism" 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."

- Exploring accessible tools, for example, a probe that can speak out loud as the data are being collected
- Vetting digital materials for accessibility, both instructions for the tools and digital places where information is being collected and documented
- Ensuring information about accommodation for service animals is readily available, and providing protective equipment for the animals
- Creating accessible virtual tours of lab facilities ("so that people can become more comfortable [and] more familiar with that space," Pérez said. "That really facilitates navigation.")
- Including ways for students to report both positive and negative
  accessibility experiences as part of fieldwork evaluations and sharing that information with future students, and in situations where
  safety is a concern, pairing up individuals with similar fieldwork
  interests.

### Artificial Intelligence and Accessibility in Educational Spaces

We can think about artificial intelligence (AI) in accessible education in different ways, Pérez said, either as replacement or augmentation. Johnston and Pérez chose to look at it as augmentation, as AI has already improved captions and may allow for a better head start on image descriptions, he said. "We really emphasize this as a way to augment and distribute potential, rather than a way to replace it," but he added that it is important to think about how this technology develops and includes people with disabilities in design and implementation—to improve the output and to minimize negative implications.

#### **KEY ADDITIONS FROM REFLECTIONS PANEL**

A panel of experts shared with Johnston and Pérez additional questions or topics their paper could discuss. Jacquelyn Chini, professor of physics and undergraduate program associate director at the University of Central Florida, said it would be useful to discuss the balance between knowledge, time, and cost for faculty. While there are resources for faculty to apply UDL principles in the classroom, basically no training is required to teach at the postsecondary level. "Sometimes we don't know the basic teaching principles let alone the accessible and inclusive principles," she said, and

that drives the need for more products for accessibility. Cost has been a challenge, she has found in her research—more expensive curricular materials have accessibility built in, while funded research may not because of a lack of money in their budget to access the support. She was interested in hearing from the panelists about solutions to make sure faculty have high-quality, inclusive, and accessible materials to use.

Developing and demonstrating STEM techniques specific to your specialization is crucial, and transitions can be a focal point, said Bradley Duerstock, professor of engineering practice at Purdue University. "Self-determination is key to developing those tools," he said, and allow you to be successful at the next educational step. "These transitions are very important and often judged in STEM by your expertise in doing a technique."

UDL discussions must be extended to consider how disabilities can be an advantage to the world of science, especially in fieldwork, said Caroline Solomon, director of the School of Science, Technology, Accessibility, Mathematics, and Public Health, or STAMP, at Gallaudet University. "When talking about individuals, we are making contributions to STEM as Deaf people," she said; for example, during scuba dives, "we can sign underwater; we don't have a communication barrier underwater, that is a benefit to us."

# Shifting Accessibility to the Beginning

One of the ways to lessen the load on faculty searching for a high-quality, accessible curriculum is focusing on procurement up front, Pérez said. "It's not a sexy topic, but it's an essential one," he said. Instead of applying accessibility at the end of the process, "we need to start early: when we consider the learning management system that we will use at our university or the library system or the lab tools we will purchase." If it is addressed earlier, then faculty or lab instructors can focus on adjusting, not starting from the beginning, he said.

Chini agreed on the shift to procurement, as well as expectations for other early-stage processes. A better future would be one where it is not just the new NSF call looking for input from disabled collaborators, but every call asks how the research is going to be accessible, especially when it is curriculum design or tools design, she said. One of the UDL principles she had seen from working STEM faculty, especially at the introductory course level, is offering students multiple ways of showing their learning, but that can be challenging given time constraints and learning management systems.

As people who are often gatekeepers, our jobs are to understand that we do not always know, and there may be multiple ways to get to the high standards education can require, Johnston said. Relatedly, she worries that, in STEM, "we cherry-pick the people with disabilities we think can be most normal or the most remediated. And we lose those opportunities for distributed intelligences," because of discomfort or unfamiliarity. You never see conversations in STEM about people who have intellectual disabilities, she added, even though they are affected by the decisions these fields make.

# Approaches for Decision-Makers

Panel moderator Dave Caudel, associate director of the Frist Center for Autism and Innovation at Vanderbilt University, asked the panel to describe potential approaches and processes for decision-makers to implement UDL. Solomon suggested testing an environment first. At Gallaudet, they were not going to set up a whole new building for labs without testing it, so they went to a warehouse and developed a mock lab, she said. They tracked how people moved in that environment, and learned a lot about how a variety of people used the space and what would be appropriate and accessible.

Including the voices of people with disabilities throughout means making sure there are open lines of communication for feedback, Pérez said. "Nothing about us without us ... too often in higher ed, we have heard this excuse of 'nobody asked for that,' but that puts the burden on the person doing the asking" and does not consider if there are mechanisms for people to ask.

Safety concerns and regulations are another way lab designs can become inaccessible, Chini said. She described an ongoing dispute about keeping mobile phones out of labs as well as an "egregious example" where a physics grad student could not get into the research space during their internship because they were a wheelchair user and were told they could not use an elevator access space because of safety rules. "These are the kind of real things that are barring folks from participating. We need to be creative about the solutions to make sure folks are safe but able to access."

It is important to have safety policies and written rules in labs and research environments, Solomon said, especially in research vessels where you may not be able to hear alarms. "If we do have good, sound policies for ship captains or managers who have already practiced in that field or in lab spaces, it will really help a lot and to document for reference ... what is and what isn't safe in the field," she said. One of the main design requirements

for an accessible lab space is to make them reconfigurable, Duerstock said. Some things must be fixed structures, but having very moveable lab benches and getting electricity from the ceiling helps in multiple ways, including improving interactions between students in labs.

# Lived Experiences of Disabled STEM Students

#### WHAT MAKES AN INCLUSIVE EDUCATIONAL SPACE

Dave Caudel, associate director of the Frist Center for Autism and Innovation at Vanderbilt University, began a panel of current and recent science, technology, engineering, and mathematics (STEM) students sharing their lived experiences by asking them about a disability-inclusive and accessible space they experienced and what made it different from other spaces.

Megan Lynch, a master's student in horticulture and agronomy at the University of California, Davis, and founder of UC Access Now, said she had never experienced an inclusive or accessible space in education or work. "The most disability-friendly and accessible space I experienced was one put together by disabled people themselves," she said, describing the summer camp activities around the release of the documentary *Crip Camp* in 2020. "Just everything about it really communicated that the people had put a lot of thought into it ahead of time in terms of what accessibility and inclusion would be." In so many other places she has been, telling someone that she has been negatively affected, "the response is usually defensive and/ or angry."

Hari Srinivasan, a doctoral neuroscience student at Vanderbilt University, said while accommodations and checkboxes are probably the first things that come to mind when considering accessibility, "it's the humanity part and empathy part and flexible mindset" that makes accessibility happen

on a continuing basis. His own experience includes an English instructor who arranged for him to participate remotely (before the pandemic) instead of dropping the semester because he could not make it in person. "She took the initiative to find work-arounds so I could be included," Srinivasan, who used a virtual voice to communicate during the panel, said. "She literally enabled accessibility." Other examples included a college biology professor who modified the final lab exam to be accessible to Srinivasan, and a lab director at a UC Berkeley lab who created a documentation role so he could be involved without having to worry about fine motor tasks. "I actually got to be involved in all the projects by giving ideas. I have learned so much about accessibility and ideas for adapting equipment for disability from my time at the lab." That experience gave him the courage and confidence that STEM could work for him. Caudel added that his most accommodating workspace is one he finds himself in now, and that is in part because his schedule and the people he works with are flexible and sensitive to his needs, much like Srinivasan's teachers.

For Stephanie Feola, a chemistry postdoctoral research associate at the University of Arkansas at Little Rock, accessible educational spaces have happened in one-on-one relationships. "It usually involved someone that recognized that I needed a different approach, or I needed extra time, or I needed something," they said. Feola echoed what Lynch shared, that accessible spaces were not necessarily in the classroom but with their peers. "I have the absolute privilege of having a group of friends where we all have various needs and we are making sure we all can be able to access things together," including sharing resources and taking notes, they said. "It's really about having a community of people who are able to use our strengths to make things accessible so that it didn't feel like we were left behind for whatever reason."

Caudel added that community was an element of accommodating and including spaces. "When you've got people pulling together, the impossible becomes pretty easy to solve," he said. He also referenced previous talks that discussed the importance of involving people with all kinds of disabilities and doing so early in the process of building a space. "I would also argue that you want to be thinking about how can we build some mechanisms in place, so if something we didn't think of comes up, that we can pivot and adjust."

# Changing the Culture

Feola said it is important to emphasize that accessibility is not a "oneand-done thing." You can set the structures, but not everything is going to fit everyone, so tools and resources must be in place to think of different ways. "Implement things are you able to implement in a scaffold ... but have the flexibility to modify in the moment," they said.

Despite the title of this overarching conference series, Disrupting Ableism and Advancing STEM, many of the panels were still talking about "mere compliance," Lynch said. "Compliance is part of what keeps people regimented in the idea we can't be flexible." Getting out of that mindset involves immediately considering accessibility. "If you have the idea to do something ... the very next moment should be how do I make it accessible? Not at the end," she said.

People who are not obviously disabled should consider disclosure, when possible, Lynch said. When her disability became "undeniable," she was candid about it, "not because I felt it was safe, [but] because I feel if people don't, nothing changes." Not everyone has the choice to "come out" as disabled, Lynch said, and those who can "really owe it to those folks and society to disclose where it's possible, because this is how we change the culture." When she arrived at her graduate program, she was still in the mindset of accommodation, likening it to requesting more comfortable manacles. But she was radicalized by an institution she called the "most viciously ableist I've ever experienced," making her wonder "why you can't care for me as a human being." It is not that policies and procedures are not important, Lynch said, but "we have to bust beyond the idea that what we are trying to do is come up with a better kind of compliance."

#### Mindset in Policies and Procedures

Training must be part of any disability policies or procedures, Caudel said, and help people understand that many of these efforts are not really all that difficult. "A lot of people are kind of afraid of them or think there may be a lot of work or effort," he said, asking the panelists what policies and procedures are needed for more inclusive and accessible spaces and cultures.

In the course of her student experience, Lynch realized she had to advocate for herself, because the "client" of the disabled student center was actually the university or school, and was organized "around avoiding litigation or winning litigation." As a result, "it's very bad for accessibility, not because they are trying to fight it, but because it's organized around the law," she said. It is especially notable that there are two disability offices, one for students and one for faculty, she added. The "last straw" for her was disability not being considered a priority for affordable graduate housing,

and almost having to live out of her car. The university takes her tuition and fees but does not want to use it when it comes to buying the things needed to make learning possible, Lynch said. "What is really crucial is to view it as the whole thing: how I get here and how I live and transport myself to work," she said, adding that college brochures show students not just in the classroom but also on campus and at events. Not all of those places are accessible, she added.

Feola echoed a similar experience with student accessibility services at their institution. "Graduate students are a second thought in regard to accessibility. Especially in research contexts," they said. Feola was encouraged to talk with the accessibility office about getting a research assistant to help with data processing, but instead was told "if I get someone to help me with my degree am I really getting my degree?' This [was said by] somebody who is supposed to help me." The accessibility office's suggestion of a screen reader did not make sense for their disabilities or their access need, they said, and it showed the need for across-the-board training for people in accessibility offices. "We know [accessibility offices] are underfunded ... [and] are highly constrained ... but we also know that there needs to be more than just following the ADA [Americans with Disabilities Act] letter," they added. Effort needs to happen at the institutional level to say this is an important thing that requires significantly more investment and involves listening to what students need. On an individual level, those working through accessibility procedures need to recognize they will make mistakes, Feola said. "What you do after the mistake is the important part.... If we are talking about STEM, we are all about learning. Grow with the new evidence."

Srinivasan was reminded of something the disability rights activist Judy Heumann talked about in her memoir: "We tend to think that equality is about treating everyone the same when it's not," he recalled. Equity of access looks different for him and others with nontraditional disabilities, and when that is not understood, it gets framed as complaining, he said. Also crucial is who gets to decide "reasonable" when considering accommodations. "There is no uniformity, which baffles the provider at the other end." The needs of autism may be considered too much work and allow for institutional loopholes. Also, some accommodations may clash, he added, for example someone with autism who needs a service animal in the same educational space as another who is terrified of dogs.

<sup>&</sup>lt;sup>1</sup> 42 USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

A key missing piece of accessibility is humanity, compassion, and empathy, Srinivasan said. It was the mindset of his high school teachers and college instructors that supported him. "It's not so much about dollar cost; it's the mindset that has allowed flexibility," he said. Bringing about that mindset shift in teachers is important, and previous research on changing outcomes for Black students by changing teacher mindsets presented a potential parallel for him. A key strategy was reminding teachers why they entered the profession in the first place.

#### TRANSITION TO WORK

#### Relationships and Barriers

Laureen Summers, project director for the Entry Point! program at the American Association for the Advancement of Science began the panel on transitioning to STEM careers for students with disabilities by identifying how important relationship building was in internships. Her program places undergraduates and graduates with disabilities in summer internships that match their skills and interests. When managers see students experiment with different accommodations and platforms for their work, they begin to understand their commonalities, including shared goals and experiences. These relationships have helped the managers to respect and appreciate the skills and competencies of their interns, she said. There is still stigma about employing students with disabilities, she noted, whether in internships or transition to full employment, often showing up as concerns about students' abilities to perform a job and their access needs. "It may be difficult to really accept others who are different, if we get afraid of what may happen to our own bodies that may change our life," Summers said, but students with disabilities have much to teach employers about problem solving, innovation, experimentation, and coping strategies. "For me, relationships are always key, and they can tell you everything."

Moderator Emily Ackerman, a postdoctoral researcher in the Lahav Lab at Harvard Medical School, asked the panelists what the biggest obstacles were when navigating from educational spaces to careers. Environments and attitudes that make it difficult for people with disabilities to get a foot in the door may be an indication of a workplace where they cannot thrive and demonstrate their talents, said Kimberly J. Osmani, senior extension associate at the K. Lisa Yang and Hock E. Tan Institute on Employment and Disability at Cornell University. Discrimination and bias in the workplace

must be discussed, and she sees it as an opportunity to educate businesses on how they can change their culture and attitudes. But some accessibility challenges limit an individual's ability to manage the interview process, Osmani said, including navigating transportation to get to an in-person job interview and the challenges of completing applications, whether it is due to inaccessible technology or to the language used on the application itself. Businesses and policymakers must be encouraged to examine their own systems and processes to really drill down what is critical to get on a job application rather than in an interview, she noted, and accept non-standard ways for people to demonstrate their skills and expertise. "There is a narrow perspective ... a lack of creativity or flexibility about what a resume should look like or what form it should take, or what an interview should look like," she said.

She also wants to increase the expectation for students with disabilities that they can be part of the workforce. "Students with disability could and should be learning about all aspects related to preparing for employment and should be equipped with the skills and the knowledge to successfully navigate the whole entire job search process," Osmani said, adding that this requires a lot of coordination across systems and in partnering with businesses for these types of opportunities.

# Apprenticeships and Building Career Aspirations

One of the ways the U.S. Department of Labor has engaged with the transition to work has been through developing pathways such as inclusive apprenticeships, said Taryn Williams, assistant secretary of the Office of Disability Employment Policy. Such apprenticeships integrate educational instruction, workforce development, and paid on-the-job training and mentorship, she said, leading to a portable national credential that contributes to job mobility. "It's not enough just to get a job. We really do want to foster and build career aspirations and the ability to move across one's interests." Successful programs in apprenticeships require collaborative partnerships and ensure a continuum of services, Williams said. Apprenticeship Inclusion Models (AIM) was a project designed specifically to be more accessible to youth with disabilities for high-demand, well-paying careers in STEM, such as information technology, advanced manufacturing, and healthcare. They tested recruitment and retention strategies for these pathways, and have built on that for their latest partnerships, Williams added, sharing more information about AIM.

As an early-career professional herself, Rasheera Dopson, a public health research assistant at the Morehouse School of Medicine, emphasized continuously engaging people with disabilities in early-career stages. "We can have all of the resources, but if people with disabilities do not know how to use them or that these resources even exist, it does them no good," Dopson said. As a first-generation college student, the experience of entering the work force and wanting to go into health policy and public health "was literally me entering a room [and] trying to figure out where all the lights are." Her internship at the American Association of People with Disabilities was not only her first encounter with people with disabilities who were college educated with sustainable careers, but they showed how it was possible to transition from their college education into the workforce in a very smooth way. "We really have to be intentional to make sure we are plugging young adults into the greater disability community, because there are a lot of disabled advocates with a plethora of resources," she said. They can serve as mentors, navigate what jobs are out there, and think about approaching work a different way, she added.

#### OVERCOMING BIAS AND STIGMA

A panel moderated by Ackerman discussed overcoming bias and stigma in educational settings and the workplace. Bias and stigma are another way of saying "unaligned expectations," Hoby Wedler, CEO of the Wedland Group, said. Those mismatched expectations can have negative consequences for the person on the receiving end. "If the expectations are not high for a person or a group, it's going to be hard for that person or group to believe in themselves enough to really push the boundaries, and push back those barriers," he said. Bias and stigma harm "our ability to thrive" in education and careers, Wedler said, when others "thinking they know when they really don't necessarily know, and putting us in compartments that maybe we don't fit into." In his own experience, he's had many people think that a Blind person should not study something "seemingly as visual" as chemistry. "It takes a lot of education, discussion, and just showing people really what is possible" to overcome that bias, he said.

#### **Attitudinal Barriers**

The biggest research finding on workplace barriers is that it is often related to the attitude of the coworkers, said Andrew Houtenville, research

director at the Institute on Disability at the University of New Hampshire. As a professor, he was taught never to demotivate a student, and he sees analogs in the stigmatizing behavior that can be present in educational settings. "Low expectations can really harm the motivation of the student," he said. "For me, that's at the heart of overcoming bias and stigma. Overcoming is not on the part of the person with a disability, it's on the part of people without disabilities."

Fear of those low expectations prevents people with invisible disabilities from getting the help they need, said L. Miché Aaron, a doctoral student at Johns Hopkins University. "I know what I need to help me succeed. Do I share that with who I'm working with and run the risk of experiencing those low expectations?" she asked, outlining potentially negative outcomes whether she disclosed her disability or not. Houtenville said that what is needed is a code of conduct for faculty that addresses multiple forms of bias, and to avoid the "hazing mentality" that exists in graduate school and particularly in STEM. "Mental health is an invisible disability many times, and it's very hard for students to communicate with faculty about it," given the stigma, he said. Ackerman connected this to the way science as a whole "values putting our bodies and minds on the line," she said. "My body cannot stay up all night. It cannot work these long hours. I cannot travel. I cannot do these things, and it doesn't make me a bad scientist. It is a fact of life for me and for many people, but there is a significant bias to the fact that I cannot do those things. "

Wedler said one way he has been able to overcome low expectations in academic settings is to directly address an instructor's bias early on. "I'd go to their office deliberately and make a point of saying, 'I know you may have concerns about me studying chemistry,'" and he encouraged professors to think about making the learning experience more accessible to him as a collaborative effort. "I teach you the best ways to teach me; you teach me all kinds of chemistry I didn't know."

# **Experiences of Accessible, Inclusive Spaces**

Ackerman asked the panel to describe a truly inclusive and accessible experience. Aaron shared that after failing her first qualifying exam, she had additional testing and discussion with her speech therapist. They worked out new strategies she could use to demonstrate her knowledge, including having a formatted structure and illustrating her answers in addition to verbal explanations. Her advisor and committee members

allowed her to make these adjustments "while keeping with the spirit of the qualifying exam." Houtenville has "always strived to give untimed exams," because for many types of disabilities, "the consequence is that it may take a little bit longer to do something."

Wedler described chemistry camps he and his mentor had created for students that tried to give them space and confidence to make mistakes. "For better or for worse, a lot of the students were very sheltered by their parents and the expectations were low," he said. But he was encouraged to see all "the students come together and feel totally free to get lost with their Blind mentors, mix chemicals, spill things if they made a mistake, whatever the case may be," he said. Through that experience, he said, "they were students who did not have to identify as Blind people. They were people who happened to be blind."

#### Strategies for Overcoming Bias

Ackerman next asked the panelists to share strategies for overcoming bias and stigma. Houtenville said he keeps the effects of ableism in mind as he teaches and designs his courses. He also thinks about the language he uses, and he has recently begun disclosing his own disability in introductions and in his National Institutes of Health biography. Before, he did not disclose because he "didn't want to have it appear as [if] I was getting any favor," for his research into disability, he said. But he recognized that was "really fear of being seen in certain ways." Disclosing his own disability is inspirational for his students, "because they may not have the same disabilities ... but it makes all the difference in the world" to know others are with them.

Wedler said that he had no choice but to come to terms with his very visible disability early on, but that allowed him to advocate for himself. "Once we own who we are and fully acknowledge who we are as individuals ... we can advocate for ourselves freely. We can speak about what we can do freely." "Self-disclosure and individual behavior is important," Houtenville said, but "there really needs to be a focus on the structural things that make someone fearful. He highlighted how power differentials in labs—regardless if they are private, public, academic, or non-academic—create more opportunities for intentional or unintentional bias to really affect people.

Aaron said she is still "trying to fully absorb the fact that I have difficulties," but she has found that identifying her accomplishments helps

increase her confidence. "Reminding yourself of who you are and what you got, definitely shakes away some of that internal bias," she said, adding that finding somebody who will be on your side when you do come up against external bias is key. "Honestly, the biggest struggle of overcoming bias is the one that's inside, the one that's popping up all because of external voices telling you things that aren't even true about yourself," she said. "Because you know who you are. You know what you want."

Ackerman said community building is important to finding that support and combatting internal and external biases. "I don't want you to feel like our only advice is to believe in yourself, because I do think that we are all up against a whole system of barriers against us," she said. She asked a related question from the audience: Is a national movement—similar to Black Lives Matter or MeToo that have been empowering for other groups in recent years—needed to make significant improvement for the disability community, and how would that be accomplished?

Houtenville said that history shows improvements for the disability community tend to come after other groups go first. "That's disappointing, but we can learn a lot. I do think that there needs to be a voice ... especially graduate-level higher education." Wedler said he is not sure "a big movement" is needed, but he agrees more needs to be done in higher education. Creating more awareness of "people with disabilities doing normal things, having normal careers" will help a lot. Aaron said a broad movement in academia would be extremely beneficial: "There's a lot of bias in academia that prevents a lot of students, well-qualified students, from showing that they have the ability to succeed in their field."

# Fostering Effective Mentorship in the STEM Ecosystem

#### THE ROLE OF MENTORSHIP IN STEM

For one of the workshops, participants came together to discuss effective mentorship for disabled people in science, technology, engineering, and mathematics (STEM) in education and in the workforce, and the transition between the two. Melissa McDaniels, associate executive director of the Center for the Improvement of Mentored Experiences in Research at the University of Wisconsin–Madison, and Edmund Asiedu, co-chair of the National Disability Mentoring Coalition, began the day with a discussion of their forthcoming commissioned paper<sup>1</sup> on the role of mentorship in disrupting ableism in STEM.

McDaniels positioned their paper in the context of the National Academies of Sciences, Engineering, and Medicine consensus report on the Science of Effective Mentorship in STEMM (science, technology, engineering, mathematics, and medicine). "This was a powerful report; it basically acknowledges there is a science of mentorship," that can frame conversations about how mentorship can disrupt ableism in STEM. She pointed out a quote from the chair of that study, Angela Byars-Winston, that "talent is equally distributed across all sociocultural groups; access and opportunity are not." The consensus study also offered a shared definition of what mentorship is, McDaniels added, as many different things can

<sup>&</sup>lt;sup>1</sup> McDaniels and Asiedu, 2023, *The Role of Mentorship in Disrupting Ableism and Advancing STEM* (https://nap.nationalacademies.org/resource/27245).

come to mind when talking about mentoring: "Mentorship is a professional working alliance in which individuals work together over time to support the personal and professional growth, development, and success of the relational partners through the provision of career and psychosocial support" (NASEM, 2019). McDaniels stressed that mentorship involves a relationship.

Some of the positive outcomes from mentorship for all people include identity affirmation, a sense of belonging and connectivity, increased self-efficacy, persistence in educational spaces and professional spaces, as well as career satisfaction and productivity. The literature, McDaniels said, indicates that high-quality mentorship offers disproportionate benefits to people from underrepresented groups (Beech et al., 2013).

# Challenges Specific to People with Disabilities

People with disabilities face specific challenges when participating in mentorships, McDaniels said. Lack of representation in education and work, as well as the challenge of disclosure, creates assumptions about the lack of mentors with similar lived experiences, especially in specific work or educational spaces. But mentorship is not just happening in dyads, McDaniels added. There is also a lack of access to career and development resources that are tailored for, and accessible to, individuals with disabilities and a history of negative mentorship experiences.

"We often think of mentorship as this wonderful thing, but not all mentoring relationships lead to important outcomes," McDaniels said. The four factors critical to promoting positive outcomes in mentorship, she said, are (1) identifying and aligning expectations between the mentor and mentee; (2) building trust in mentoring relationships, especially where one of the individuals has a disability and the other does not; (3) self-reflection by both parties; and (4) mentorship education.

#### **Roles for Mentors**

Asiedu continued the presentation by discussing roles mentors of people with disabilities can take on. Mentors can have the same expectations for mentees with disabilities as those who do not have disabilities, he said. "We are highlighting this because we would want a situation where mentors will say, Okay, I believe in this person. This person has what it takes to get to this goal." Mentors can also disclose their own disability, if applicable.

That builds trust, he added, and helps the two to be connected in a way that promotes the mentorship relationship. Importantly, mentors must share expectations for themselves as well as mentees, he noted. One thing Asiedu remembered from his own mentors is that they were "constantly reminding me of how much they were interested in my success.... That really kept me on track." Discussion of expectations must also include what specific roles the mentor will take on, for example, career guidance, meeting other professionals, or solving workplace challenges, and how often and where they will meet.

"It is so important that as a mentor, you develop a unique way of listening to your mentee and listening to what they share," Asiedu said, including asking them about their own lived experience and to reflect on their own identity as an individual with or without a disability. Mentors are role models, not only in careers but in other aspects, especially if the mentee wants to be an advocate or fulfill a specific role in their STEM field, he said. Mentors can educate themselves about best practices in mentorship, learn about different types of disabilities and the disability of their mentee, and be aware of career and development resources. "If you are a researcher and mentoring somebody whose main goal is to become a researcher, make sure you have access to other resources that will be useful to the development of this individual ... and then you keep sharing that when needed," Asiedu said. This also includes searching for accommodations and understanding the accessibility of the resources and opportunities you are connecting them with, he added. Mentors can also ask mentees if they use person-first or identity-first language, and protect what is disclosed to them about disability status, unless the mentee has given them the authority to be open about it.

#### **Roles for Mentees**

Mentees have their own roles to consider, Asiedu said. This includes understanding the value of having mentors with or without disabilities and exploring different ways to find the right mentors. Alumni groups and organizations focused on people with disabilities may offer suggestions, as well as organizations and people who are in the fields and professions you are interested in, he said. Mentees should try to disclose their disabilities to their mentor early, if possible. "I know that some people delay that because they are stigmatized as a result," he said, but in a mentorship, that disclosure will be super helpful to the relationship. Mentees need to be proactive in

asking questions, setting short- and long-term goals, and meeting regularly so the relationship does not fall apart. "Take responsibility for the agenda and plan," he said. "Don't be dependent on your mentor. You can develop that in partnership with the mentor."

"Mentors and mentees each have agency" in the process, McDaniels said, but there are also important roles for educational institutions, employers, and national organizations. Educational institutions and other employers in STEM can create employee support groups and other services, create programming around national disability mentoring day, and consider the role of mentors and mentorship in their policies for critical transition moments, such as hiring, onboarding, and graduation, she said. Organizations can also create mentoring awards, educate the entire workforce on disability etiquette, and fulfill their role in providing accommodations, she added.

#### **Roles for Organizations**

National organizations focused on disabilities and STEM mentorship can contribute by increasing awareness of inclusive mentoring, recognize mentors and mentoring programs for their contributions toward inclusive mentoring, and promote evidence-based practices that improve mentorship relationships for all people, Asiedu said. Rupa Sheth Valdez, associate director of the Department of Public Health Sciences and the Department of Systems and Information Engineering at the University of Virginia, asked what the first steps an individual can take if they are thinking about mentoring disabled individuals and how they can be a more effective and responsive mentor.

"Being aware of oneself matters," Asiedu said. "It supersedes everything. Once you know yourself, you know the limits. You know what you can do." Being resourceful and targeting the help toward the interests of the mentees is crucial, he said. "You want to arm yourself with all of these resources."

#### MENTORSHIP PAIRS SHARE THEIR EXPERIENCES

Michele Cooke, professor of geosciences at the University of Massachusetts Amherst, introduced the next part of the workshop by sharing her own successful mentoring experience. Meeting her mentor in her master's program, who was also Deaf and Hard of Hearing, "changed my perspective on professionalism possibilities.... Meeting that person made me elevate my goal." There is a wide spectrum of who can be a mentor, Cooke said. "Mentors can be disabled, abled; they can be a coach and they can be a peer. They can be a colleague."

## Accessibility Adaptations Can Benefit Everyone

Hoby Wedler, CEO of the Wedland Group, and Dean Tantillo, professor of chemistry at the University of California, Davis, spoke about their collaborative mentorship partnership as far back as Wedler's undergraduate years. When Wedler joined Tantillo's group, their approach was one of talking about both scientific problems and accessibility problems, then working together to remove roadblocks. Tantillo also encouraged him to apply to graduate school, and Wedler eventually joined his group as a Ph.D. student.

"It was an opportunity for us to test out how computational chemistry would work for me and how we could make things accessible in the lab," Wedler said, including making 3-D printouts of molecule visualizations to be held and manipulated. "I think a lot of what we decided and discovered ... was a lot of the sighted students in the lab found our techniques useful and productive for them as well. "We used to call it Hoby's rule," Tantillo said. "Anything we develop for Hoby has to be useful for sighted people as well." It was said jokingly, but such a framework was not only helpful for other people but allowed for wider acceptance and rapid development of technology or processes. Another major learning experience for Wedler when working with Tantillo's group was what can happen for disabled students when they are given a chance. "You can step out there and give it a try," when an instructor like Tantillo involves people who may not know what their true potential is. "You unlock it. You pull it out of them," he said. That's what it means to be a teacher, Tantillo said. "If you are going to be a good teacher, you have to tune in to your students and understand what their needs are and what their style is," helping everyone to make the most of their potential and provide opportunities and tools to do that.

The benefits of their mentorship also extended to other students and instructors, especially when they put together a chemistry camp for students with disabilities that attracted attendees from around the country, Wedler said. "We can take something like that and get other people excited about the things we are excited about in order to move forward and create the best possible future for as many people as possible." Tantillo said Wedler had gotten him thinking differently about both scientific problems and

nonscientific problems. "I want to challenge the way I think about things, and it is always, always a pleasure to puzzle things out with you," Tantillo said. Both of them share the philosophy that they "don't focus on what can't be done. Instead, we focus on what can be done. Even if it is small steps forward, just moving forward is the important thing."

#### Access and Inclusion

Raja Kushalnagar, director of the Information Technology undergraduate program and Accessible Human-Centered Computing graduate program at Gallaudet University, and Matthew Seita, a recent computing and information sciences graduate at the Rochester Institute of Technology (RIT), discussed their experiences working together at RIT, as well as other mentoring experiences as Deaf people. The two met when Seita was in a program encouraging students who were Deaf and Hard of Hearing to learn about computer systems. Seita said it was his first experience learning about research on accessibility, among other things. "I saw a Deaf person in research at the university, and they had a similar experience to me," he said, adding it was a way to learn about what other Deaf people were doing out in the field.

Kushalnagar said his initial experience at graduate school at RIT was similar, but during his Ph.D., there was no community of Deaf individuals in his program. "It was a very tough and a very isolating thing." he said. An ally, Richard Ladner, was a hearing person and had set up a program at the school with hearing people who could sign and were involved in research. "Instead of just helping, they were also learning the computer profession as well," Kushalnagar said. He was encouraged to be a mentor himself going forward. Seita said that college could be isolating for him as well, but the research program he participated in with Kushalnagar helped integrate him into the wider research community, helped him improve, and gave him the experience of presenting his work at a meeting, which helped him to meet more people who were researching the same thing.

Kushalnagar's mentor mindset includes both accessibility and inclusion, and that is why his group was not Deaf-only. "We have access, but we also need inclusion," he said. This adds to the number of people who are sharing their perspectives and sharing different experiences to grow together. Seita noted a time when people were verbally talking in a lab, and he missed out on their conversation. "I really needed people who were more willing to work with me and to provide that inclusion," he said.

It helps a lot to have shared interests in research and shared experiences with challenges, Kushalnagar said. "Maybe our experiences are differing in some ways, but it is building a better product and building a better community." He is looking forward to seeing what happens in the future with a more diverse group of faculty, internships, and professionals. Building relationships professionally across people who are Deaf and allies, as well as people with different disabilities, has a significant effect, Seita said. Having an advisor he can directly communicate with, either through ASL (American Sign Language) or the written word, is really important. "If there isn't an interpreter, the communication sort of breaks down"; interpretation does not come directly from the person he is getting advice from.

## Communication across Multiple Methods

Another conversation featured two students, Loam Shin and Michelle Olson, both at the Rochester Institute of Technology, and their advisor, Kristen Shinohara, assistant professor in the School of Information at RIT. Shin had "heard great things" about Shinohara. "I knew she was a researcher and that interested me." They got involved in a project focused on user interface design in technology for Deaf and Hard of Hearing researchers and designers. They planned how they were going to approach the project by talking about user-friendly technology specifications, brainstorming different ideas for the technology, and contemplating the interactions people would have with it. "It wasn't easy at first, I'll be honest, because I use ASL," Shin said. "Deaf people who use ASL such as myself, we are very hands-on people. We use our hands as much as possible. It is tough to find ways that will play to those strengths."

Olson is part of the National Technical Institute for the Deaf, located on RIT's campus. She enrolled there because she wanted to find a major that was inclusive for her language, and she wanted to study STEM. Olson called it a great pathway to success, where "both Deaf and hearing people can work together online and in person. It has been a streamlined process." Having multiple communities on campus makes for a great environment, she added.

Shinohara noted that she is a hearing person and both Olson and Shin are ASL signers. She asked the students for their perspective about how they work together. Olson said it was a different experience compared with an all-Deaf mentor group or an all-signing mentor group, but "they still always work hard together," and Shinohara is a great person to challenge

them and bounce ideas off of. They prioritize getting interpreters for their meetings, but also do a lot of work over email and Slack.<sup>2</sup> Olson added that it is nice to have Shin to brainstorm together in their native language, and it is important to have two ASL signers involved for the nature of their work. Shin said she agreed. "It is a privilege to work with Kristen. People like her keep it interesting....We have a lot of values in this group that are shared. It is accessible and that's what is most important to me."

Shinohara asked them, based on their current experience, what they are looking for in future mentoring experiences. Shin said it was important to find someone who is willing to work with you no matter your accommodations, and make accessibility a given. "Having an interpreter is crucial. Making sure that we get all of the terminology, and we don't miss anything, that's crucial," she said. Olson said that one of the major elements she wants to carry to future meetings and mentorships is providing an agenda before they meet.

Shinohara said she had resources at her institution to develop that mentorship relationship, including quite a large team of ASL interpreters and a system for scheduling them, which is often not the case at other universities. "This is the first priority I have when we are setting up meetings is to make sure we have that support," she said. If she was not at RIT, from a faculty member perspective, she would want to find grant funding or other departmental services to do so.

# MUTUAL MENTORSHIP IN THE DISABLED STEM COMMUNITY

Logan Gin, assistant director of STEM education, Sheridan Center for Teaching and Learning at Brown University, moderated a panel on ways people with disabilities in STEM offer mentorship and community building with each other.

Ana Caicedo, professor of biology at the University of Massachusetts Amherst, began the blog *The Mind Hears*, written by and for Deaf and Hard of Hearing academics, with fellow UMass colleague Michele Cooke in 2018.<sup>3</sup> They had two main goals in mind, Caicedo said. First, "as scientists with hearing loss at a predominantly hearing institution, we felt very

<sup>&</sup>lt;sup>2</sup> Slack is an instant messaging and workplace communications tool; for more information, see https://slack.com/.

<sup>&</sup>lt;sup>3</sup> Available at https://themindhears.org/.

isolated," she said. By creating the blog, they could reach others and build a network of academics with hearing loss, decrease the isolation that many of them felt. Second, they felt they were "constantly reinventing the wheel" trying to meet the recurrent challenges of teaching, service, and research duties, and were not sure they were coming up with the best strategies. The blog became a forum for peer mentoring, to share experiences and potential solutions to professional challenges, she said. *The Mind Hears* publishes every 3 weeks, written by Caicedo or Cooke or other contributors. There are a variety of post types; Caicedo's favorite are profiles of Deaf and Hard of Hearing academics in various fields and career stages. They have also started informal drop-in chat sessions via Zoom to connect more with other Deaf and Hard of Hearing academics.

Alyssa Paparella, a Ph.D. candidate at the Baylor College of Medicine, started a platform called DisabledInSTEM because she wanted to make a difference for disabled scientists. She began on social media and with a website, then expanded to a mentorship program. We wanted to know I wasn't the only disabled scientist out there, and she offers discussions and more representation to disabled scientists. Paparella valued having a mentor when she was an undergraduate, but he was not a disabled person and did not understand the barriers and obstacles she faced. We wanted to create a community where even if [their mentor] wasn't a disabled mentor, they could share their experience with fellow mentees and have the support network.

Edward Manyibe is the research director at the Rehabilitation Research and Training Center at Langston University, a historically Black college and university in Oklahoma. The center focuses on employment equity for multiply marginalized people with disabilities, and he is the co-principal investigator of a project designed to mentor postdocs interested in research in the fields of disability and rehabilitation.

Erica Avery, a recent Ph.D. graduate in physiology from Johns Hopkins University, is one of the founders of the Equal Access in Science and Medicine committee.<sup>5</sup> Her group "quickly turned into a very tight-knit community. We realized that there is such a need for community among people with disabilities in our field." They work with leadership and student disability services to improve access, change the culture, and "really raise our voices," including building their own programming: a lecture series of

<sup>&</sup>lt;sup>4</sup> For more information, see https://disabledinstem.wordpress.com.

<sup>&</sup>lt;sup>5</sup> For more information, see https://equalaccesshopkins.com/.

disabled speakers, disability pride month, book clubs, listening sessions, and panels.

#### Lessons Learned

One of her biggest lessons from developing the mentorship program was accepting feedback and critique from others, Paparella said. "I started a program of how I thought [it] would fit the best needs for people, but it doesn't mean that's exactly how it needs to be envisioned." The program was originally one-on-one mentoring, where pairs connected on their own. Based on the feedback she was getting, she now incorporates pod mentoring or mutual mentoring, where there are three mentors per group and between five and seven mentees. This creates a group structure that avoids one person becoming overwhelmed, she said. "In the case of a mentor, sometimes they just get burdened in a year-long program, as things have come up that they may not have expected." A pod structure allows for people to learn from each other across the mentor-mentee relationship. "This is something I wouldn't have considered if I didn't take the feedback from others," she said.

Caicedo shared that it has been "sobering" to realize that the amount of work it takes to sustain "even a loose mentoring effort" like their blog is greater than it appears. Managing *The Mind Hears* has been immensely gratifying and created the peer mentoring network that they needed, but the work competes with the rest of their academic obligations. "Learning how to balance the work on the blog with everything else we have to do is sort of an ongoing journey," she said.

Avery agreed that there was isolation between disabled students at her institution. In some of the surveys they did, more than one-third who identified as disabled had not registered with student disability services, nor disclosed to anyone around them. "It was very difficult to find each other," she said. "When we felt frustrated with policies in place or decisions from university leadership, we always are wondering if it was just me ... we have learned through having a community that we weren't alone at all." Just having people who also understand what you are going through is so meaningful, Avery noted. Peer mentorship is "how I really started to learn I didn't need to shrink myself or make myself invisible.... I really began to deprogram from the internalized ableism," especially from working at a medical institution.

Minority-serving institutions are underrepresented in receiving federal grants, Manyibe said, but their program is geared toward developing

researchers who can secure grants and continue to be role models in their field, so they source mentors from other universities. They also learned that there is no single mode of mentorship that can serve everyone, and they have developed several models: peer-to-peer mentorship for faculty members across minority-serving institutions, multiple peer mentorship for postdoc researchers, early intervention models for students' postsecondary education, and a short-term mentorship program where faculty from other institutions are integrated into the project so that they understand how to write and manage a grant. "There's no way one mentor can ... meet the needs of each person," Manyibe said, so there is a need for multiple mentors. For example, a person with a disability may need a mentor who also has a disability but also one who has experience doing research, and one who understands how to develop relationships and manage time as an academic.

## Different Aspects of Life and Disclosure

The Mind Hears is targeted at graduate students and later academic career stages, Caicedo said, because their experience was that the support structures became weaker and weaker higher up the career ladder. "For example, disability services in universities will usually know how to help a Deaf student who is taking classes. But then when the instructor is Deaf, they are more lost about how to help out in that situation or how to help out a faculty member who has to present at a conference," she said. Some situations they have covered include how to teach effectively, participate in conferences with a hearing loss, navigate faculty meetings, carry out fieldwork, and disclose deafness when applying for jobs.

Paparella's mentorship program ranges from high school to faculty, so they cover a wide range of situations and issues. Most often, people are concerned about disclosure, including how and when, and the process of getting accommodations, "especially if you are not certain and haven't had experience to be in a lab to know what tools or accessibility issues you have." Mentees want to learn how to feel empowered in the lab work they want to do, she said. It is hard to balance how you feel about disclosing with feeling safe to do so, Avery said. "I disclose because, really, I am just too tired. I don't want to be invisible. I don't want to shrink myself," she said, but doing so has led to instances of retaliation.

Refraining from disclosing can also affect opportunities to bond. For example, Avery was once working in the same department as another student who founded her group, but they had no idea they both had chronic

illnesses; instead, they found each other through a graduate student association meeting. A primary issue that arises with their group is dealing with toxic hustle culture and tokenism. They have been leading the charge to create programming, build accepting spaces, and celebrate the efforts of students with disabilities.

Universities have also been pushing to "return to normal" by taking away pandemic-era changes that benefitted disabled people, such as asynchronous learning, teleconferencing, and working from home, and Avery's group is focusing on pushing back, "trying to get that message through to leadership." They also teach faculty to lift up the voices of disabled colleagues and promote a better inclusive culture, she said. The group also offers mentorship through positive conversations about management and symptoms for people in school with chronic illnesses: "There are so many disabilities out there and there are so many represented in our group, but we connect on so many levels about what our experiences are and how to ... manage the barriers."

# **Defining Roles and Expectations**

Gin asked Paparella and the other panelists how they define roles for mutual mentors. This year, Paparella asked mentors to contribute by meeting with mentees once a month, then asked the mentorship groups to find a topic each month they would be interested in discussing as a group. She asks for each group to have a designated note taker, and each time, a different pod group shares their notes with the entire program. "So, you are learning from other discussions you might not be a part of." There is also a Slack channel for people to have informal conversations, she added.

Research is very intense, and Langston University has designed their mentorship programs to cover a long period of time, as long as 5 years, to help people not feel pressure that they have to do things quickly, Manyibe said. They also meet with mentees to understand what is going on in their lives. "Historically Black colleges and universities are known for having close relationships for students," he said, and that close relationship is important in terms of mentorship. During the pandemic, his program was dealing with more personal issues as people were struggling with the isolation from their family members and trying to provide support. That is part of the mentorship, he said. "If someone is not healthy, they're not going to be productive in research. So, we had to make sure that we attend to those aspects."

# Visibility and Training

An audience member asked what can be done to make sure leaders have the training to mentor and make sure it is equitably available. Formal mentorships are not offered to everyone, Manyibe said, so they are in constant discussion with university leadership about how they can take what they learn and spread it to the whole university. But expanding mentorship goes back to the concept of investment, Manyibe said. "Mentorship is intensive," and at minority-serving institutions there are not as many mentors, and those who take it on are already overburdened with teaching and other responsibilities. They advise looking for mentorship programs for faculty outside the institution, including options at the National Institutes of Health and the U.S. National Science Foundation and at broader online mentorships.

Another audience member asked how to increase the visibility of people with disabilities among academic faculty and more senior folks to make it easier for disabled students to feel like they belong or feel safe disclosing themselves. The more we encourage everybody in academic settings and other settings to view disability as part of diversity—especially given the push for diversity, equity, and inclusion (DEI) initiatives—disabled faculty can become more visible to students, Caicedo said. Avery agreed and said that "out lists" LGBTQIA+ faculty could join encouraged students and others to feel safe, but "there was a lot of fear" around a similar concept for disability. "I can understand why people, especially faculty, would not feel comfortable being visible in order to have relationships and mentoring," she said. Hiring disability experts for DEI offices and other interventions would create a safer environment for faculty to be visible, she added. It is also the reason students are probably more represented in the disability community than are faculty, Avery added, and it is a huge burden on the few that do and have mentoring and supportive relationships with students.

Paparella agreed and said that it was up to wider institutions to build this visibility and the conditions that allow it. "I also want to challenge everybody who is [here] right now, as an ally or somebody interested in learning about disability, what are you doing when it comes to conferences or your societies that you are part of? … I would really hope that you take this lesson and do a reflection of your own institution and societies and the conferences you attend," she said.

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# Understanding Workforce Barriers and Reimagining Access

#### BARRIERS AND UNMET NEEDS

Another workshop began with Kate Mittendorf, a senior staff scientist at the Vanderbilt-Ingram Cancer Center, presenting an overview of their commissioned paper¹ on common workforce barriers to meaningful access in science, technology, engineering, and mathematics (STEM). "The conclusion of this review is not some checklist whereby you can just go mark off your access needs: boom, done, access is over," Mittendorf said. Instead, they grounded their work in thinking of access as a verb, using a familiar example: the classic wheelchair icon, changed to show the person leaning forward with their arms behind them, as if they are pushing the wheelchair, and angled cutouts in the circle to indicate motion. "It's not to say that every person who uses a wheelchair is able to manually push them but to instead reframe access as this active rather than passive concept," they said.

While checklists can be excellent tools to begin to build access, many access barriers in the workplace are rooted in ableism and resulting disableism,<sup>2</sup> Mittendorf said: "Creating meaningful access requires active

<sup>&</sup>lt;sup>1</sup> Mittendorf, 2023, Reimagining Access: Critical Examination of Barriers to Full STEM Workforce Participation for Disabled Individuals (https://nap.nationalacademies.org/resource/27245).

<sup>&</sup>lt;sup>2</sup> There are two spelling conventions "disableism" and "disablism" 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."

engagement." This extends to universal design, they added, quoting from Jay Timothy Dolmage's (2017) *Academic Ableism: Disability and Higher Education*: "Universal design should be registered as action—a patterning of engagement and effort.... Such [check]lists invite us to believe that universal design would stop if all the boxes were checked. We should be more interested in places to start thinking, doing, acting and moving." Mittendorf classified the barriers in the workforce into four high-level categories: infrastructure, policies and procedures, culture, and unmet needs, highlighting a few examples of each.

#### Infrastructure

Infrastructure is most commonly thought of as the built environment, and the "ADA [Americans with Disabilities Act³] is pretty insufficient for defining access for built environments, especially specialized spaces like laboratories," they noted. But infrastructure also extends to information technology decisions a workplace makes, inequitable access to training and conferences, and lack of needed insurance benefits for disabled employees, including mental health care.

Because software—from a human resources (HR) portal to video conferencing to word processing—can completely vary in accessibility features, an organization's selection of programs is significant, Mittendorf said. At conferences and career development training it is disabling not to be able to access materials or physical locations. In one example they highlighted, the lack of a ramp to the podium prevented speakers from taking the stage on their own panel. "Conferences are historically very difficult to access, and that creates career barriers for STEM folks with disabilities," Mittendorf said. "So you have to weigh meeting with like a million access barriers against the career opportunities and networking conferences afford, every time one comes up in the field."

#### **Policies and Procedures**

Blanket job description policies from HR are one example of policies and procedures building in barriers to disabled people in STEM. Mittendorf explained that their own job description includes physical requirements

 $<sup>^3</sup>$  42 USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

unnecessary to their work and they cannot accomplish, but they are there because HR requires a set of the same skills to be in every listing. "When those requirements are listed, you have to think to yourself, Are these ... meant to screen out people like me?" they said. "And is this intentionally an exclusionary workplace?"

Accommodations can also have a "double-edge sword," through framing access as a privilege or a gift. This framing can be harmful to the perception of the disabled person in the workplace, Mittendorf noted, and policies that place a high emphasis on legal compliance turn into gatekeeping. This emphasis forces those with disabilities to prove their disability through "detailed descriptions of our illnesses and disabilities" and normalizes what Mia Mingus calls "forced intimacy," Mittendorf explained.

The process of accommodations can be lengthy and costly, requiring several rounds of medical documentation, they added, which is increasingly burdensome for marginalized people whose access to health care could be affected. "The whole time they are going through this process, they are working with an unmet access need, and that means you can't work the way you want to or maybe you can't work at all, and that sets us at an unfair disadvantage," Mittendorf said. While these barriers are grounded in a wider ableist culture, they added, STEM fields have specific values that can be at odds with access: the medical model, assumption of nondisabled objectivity, productivity, and independence. Because the medical model was created by a nondisabled scientific workforce, it assumes a nondisabled lens is the objective one. This applies to both interpreting data, Mittendorf said, as well as how disabled people are viewed in the workplace.

#### Culture

The cultural values of high productivity and the "pedestal position" of the independent investigator contribute to negative stereotypes of scientists with disabilities, Mittendorf said. "I'm aware that having a sparse publication record because I'm not allowed to work full time ... is inevitably going to have a negative impact on me," they explained. Reframing STEM values through a disability justice lens, such as focusing on interdependence, not independence, "can foster a more collaborative and multidisciplinary

<sup>&</sup>lt;sup>4</sup> Mingus, Mia. "Forced Intimacy: An Ableist Norm." Leaving Evidence (blog). Wordpress.com. August 6, 2017. https://leavingevidence.wordpress.com/2017/08/06/forced-intimacy-an-ableist-norm/.

approach," they added. "Interdependence is key to good collaborative science."

#### Unmet Needs

Even with accommodations in place, individuals may still have unmet access needs because a workplace has taken a descriptive approach, only offering "a menu of all the possible accommodations that a workplace is willing to give you," Mittendorf said. Each individual and disability is unique, so it can be impossible to anticipate every need. A creative approach that centers the individual is an example of access as a verb: "When you work with an individual to identify an unmet access need and creatively meet them, you're more likely to bring them access," they noted.

## TOOLS AND REIMAGINING JUSTICE

Mittendorf highlighted some tools for both people in STEM fields with disabilities and employers, including the Employer Assistance and Resource Network, or EARN; AccessSTEM, the Job Accommodation Network, resources collated by the Royal Geographic Society, and SIGACCESS, among others. They also encouraged rethinking meaningful access to STEM and reimagining justice for the disabled STEM workforce by applying concepts from the disability justice movement.

Historically, people with disabilities have not been able to participate in the "acceptable knowledge about us," Mittendorf said, because of a combination of assumptions of objectivity and what they call "academy lock-out." Instead, disabled people generate knowledge in the margins—memoir, blogs, social media—simply by navigating a world where "our access needs are going unmet by design." These "cripsistemologies," as Lisa Duggan describes them, should not be counted less (Hammel, 2006). When "granting" accommodations, whose knowledge of access are we centering? Mittendorf asked.

Mittendorf also questioned how the STEM workforce operates: Is there really only one way to work? To illustrate the value of interdependence, they related a Glen Everett story in the essay collection *Uncharted* 

<sup>&</sup>lt;sup>5</sup> For more information about EARN, see https://askearn.org/; for AccessSTEM, see https://www.accessstem.org/; for the Job Accommodation Network, see https://askjan.org/; for the Royal Geographic Society, see RGS, n.d. (in References); and for SIGACCESS, see http://www.sigaccess.org/.

by Skylar Bayer and Gabriela Serrato Marks.<sup>6</sup> During field research, Everett was paired with a colleague whose main role was to knock on inaccessible doors and ask people to speak with Everett. But when they arrived at the first accessible street, they found it was entirely residents who did not speak English but did speak his colleague's native language. "To me it really shows that the disability justice value of interdependence can have a big impact on the way we accomplish our work," they said.

Meaningful access to workplaces and workforce "comes down to culture" Mittendorf said. They suggested publicizing accommodation processes to all employees when they are introduced to the workplace, explaining how it works and encouraging new employees to speak up about individual unmet access needs that prevent them from being successful in the role. Managers, supervisors, and HR staff need to be trained to move away from "access as a gift" mindset, they said, instead thinking of access as "something everybody should be creatively trying to build together."

#### REFLECTIONS

Anita Stone Marshall, a lecturer in geosciences at the University of Florida and executive director of the International Association for Geoscience Diversity, began the reflections on Mittendorf's paper by asking how to better use existing tools and how those tools can be improved.

Process is just as important as tools, especially in the private sector, said Sheri Byrne-Haber, an accessibility architect for VMWare and the author of the *This Week in Accessibility* blog. "We need to make sure that the processes have been established to make sure that the tools get used," she said. A tool-based accommodation can also be a solution for one person, but it does not remove the actual barrier, Byrne-Haber said, giving the example of someone assuming the need is the same for every wheelchair user. "That isn't always the case, and at the end of the day, you've removed the barrier *maybe* for the one wheelchair user, but you haven't removed the barrier for everybody." This is especially not recognized with progressive or intermittent disabilities, she added. What works today may not work next week. "The accommodations teams will think, Okay, I solved this problem, I'm closing

<sup>&</sup>lt;sup>6</sup> Skylar Bayer and Gabriela Serrato Marks, *Uncharted: How Scientists Navigate Their Own Health, Research, and Experiences of Bias* (New York: Columbia University Press, 2023).

<sup>&</sup>lt;sup>7</sup> Available at https://sheribyrnehaber.medium.com/this-week-in-accessibility-what-we-can-learn-from-the-webaim-million-2c11540fd46d.

out the case," she said. "The person might have to come back ... later and say, Hey, you know what? This isn't working for me anymore."

Rory Cooper, founding director of the Human Engineering Research Laboratories at the University of Pittsburgh, also pointed to tools being most useful when workforces can reach "critical mass" on accessibility as a practice and as part of the culture. When there are enough people with disabilities—disclosed or not—in the organization working alongside their colleagues without disabilities, culture change is possible, Cooper said. That is why he advocates "very strongly" for hiring more disabled employees and listening and learning from them. "Accessibility is just an entry point," he said. "The real point is to be productive, to have career options, career pathways, and we can do that by integrating ourselves into the organization, into the community."

Joey Ramp-Adams, founder and CEO of Empower Ability Consulting, Inc., gave an example of what happens when disabled people are not fully integrated into STEM workforces, especially as decision-makers. While working with a tier one research university on their medical school's diversity, equity, and inclusion (DEI) strategic plan, she noticed there was not a single mention of disability in the entire document. Disability had been "completely overlooked" in the plan until Ramp-Adams brought it to their attention. "So, obviously, no one on the committee was disabled. No one even noticed for 2 years," she said. Her own experience working as a consultant has repeatedly showed companies will prohibit discrimination for people with disabilities, but ignore the stigma, she said.

While we often think about tools as physical objects or a piece of software, Marshall noted, expanding the idea of access tools to include people and animals may require additional considerations. Ramp-Adams said she deals every day with people wanting to pet and interact with her service dog, which in itself is disabling. There is also common misunderstanding that service dogs need to be with their person 24/7, which leads to some thinking anything less than that means they are misrepresenting their need, she added. "Someone who uses a service dog for balance and grace can use a wheelchair for a day," Ramp-Adams said. "Sometimes with invisible disabilities, people can also manage their disability for the short term, away from their service dog," including medication, human assistants, or other means. Education about how to interact with service animals, human assistants, and the broader conceptions of accessibility tools is needed, she added.

Cooper noted that assistance can also include help with specific pieces of equipment or processes, for example, a medical student who uses another

person to demonstrate their skills about how to do a physical exam. It is crucial to think about such assistance as part of "team science" and wider collaboration, he added, and think about similar ways nondisabled colleagues are helped by the same or other tools. "In the labs we work in, the buildings we work in, they're all tools ... whether they drove to work or took public transportation or walked or rode a bicycle, they're all tools," he said. "What I find funny is that every organization is pretty quick to adapt tools for productivity, and not tools for accommodation, but really the tools for accommodation are productivity tools."

Marshall asked what policymakers and decision-makers should keep in mind when trying to remove barriers in STEM workplaces. Byrne-Haber noted that, currently, there is not one standard for digital accessibility adopted by the federal government, and it has led to different court decisions in different districts. Making a version of the global Web Content Accessibility Guidelines, or WCAG, standard<sup>8</sup> and associated with the ADA would "establish in concrete what the expectations are," across the United States, Byrne-Haber said. "Because right now, there's room for companies to kind of 'weasel out,' saying, Well, I don't really know what I'm supposed to be doing, because there's no official standard."

Cooper also cited the current income cap for coverage of personal attendant or personal assistant care, calling for it to be removed. Many people might get a STEM-related degree but "can't work because they would lose their medical assistance care.... They get stuck in an unrealistic position."

Byrne-Haber pointed out that the pipeline to get disabled people into STEM careers was very different on a state-by-state basis because of how each state's education system treats people with disabilities. She mentioned Massachusetts has an "outstanding" high school graduate rate for people who have IEPs (Individualized Education Programs), or 504 plans, <sup>10</sup> which would be largely children with disabilities, while Nevada's rate for similar students is "atrocious." "When you've got poor graduation rates, you're

 $<sup>^{8}\</sup> For\ more\ information, see \ https://www.w3.org/WAI/standards-guidelines/wcag/.$ 

<sup>9 42</sup> USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

<sup>&</sup>lt;sup>10</sup> For more information on IEPs, see https://www.edweek.org/teaching-learning/what-is-an-iep-individualized-education-programs-explained/2023/07; for more information on 504 plans, see Section 504 of the Rehabilitation Act of 1973, as amended, at https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973.

going to have poor college attendance rates ... poor grad school rates," she said. "People drop out because they can't handle both the financial burden of being a student and the financial burden of having a disability, because there is a tax to us." She called for more financial support for tutoring and transportation.

Ramp-Adams said one of the barriers Mittendorf identified, access fatigue, is something she sees every day. Students she works with are constantly forced to provide medical documentation to enter spaces with their service dogs, and "reasonable accommodations" are left up to very subjective interpretation. In one day, she can help people in the same state with very similar situations, but with completely polar opposite results. "These students just burn out and they quit, and we lose them out of that pipeline," Ramp-Adams said.

As the panel finished their reflections, two speakers noted how important it was to include disability and accessibility into workplace DEI efforts. "If I could wave a magic wand, it would be to make sure that any time DEI comes up, include disability," Byrne-Haber said. "There is no reason that we should be excluded or [out of] benign ignorance left out of DEI initiatives." "We are the largest minority, and we need to be included," said Mona Minkara, planning committee member and head of the Computational Modeling for BioInterface Engineering, or COMBINE, Lab in the Department of Bioengineering at Northeastern University.

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# Creating Disability-Inclusive Workforces and Workspaces

#### THE COMPLEXITIES OF WORKPLACE ECOSYSTEMS

During the workshop summit, panelists from different parts of the science, technology, engineering, and mathematics (STEM) ecosystem—the private sector, federal funders, publications, universities, and philanthropy—discussed their perspectives on including disabled people fully in the workforce. "If we are going to disrupt ableism, there is opportunity for multiple sectors to come together to do that," said panel moderator Andrew Imparato, executive director of Disability Rights California and a member of the Beyond Compliance: Promoting the Success of People with Disabilities in the STEM Workforce Committee.

#### National Institutes of Health's Role

Alison Cernich, deputy director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH), said that "with great humility," NIH had made a start on addressing ableism both internally and externally. That work was driven by a committed group of people inside and outside of NIH who produced a report in December 2022 on ensuring inclusion of the disability community in the institutes' work, including a roadmap that was "immediately integrated" into an NIH-wide strategic plan on diversity, equity, inclusion, and accessibility (DEIA). She noted that NIH knows

more needs to be done to promote inclusion. "We need to address ableism in our training, in our communication, in [our] policies, and in our structures. We really need to make sure that anti-ableism is a core component of our DEIA work," she said, adding she expected to be heavily involved in this.

NIH's role as a funder is also crucial, Cernich said, both in the topics they fund and how disabled researchers are involved. NIH currently funds extramural research that examines bias and discrimination consistent with ableism, but "we need to do more to drive evidence in this area," she said. One example, she added, was recent funding of the work of Lisa Iezzoni¹ looking at discrimination and stigma by medical providers, which Cernich said calls out "the need for training and education on how to provide care that respects the health and wellness of people with disabilities."

NIH is trying to address inaccessibility in their own work ecosystem, including a way to report inaccessibility or environmental barriers on the NIH campus, and better compliance with section 508,<sup>2</sup> "which I've told people is not a strategy, but a legal requirement," she emphasized. "We are engaging our community to help guide us," Cernich said, specifically thanking Theresa Cruz, director of the NICHD National Center for Medical Rehabilitation Research, who sponsored a workshop on ableism in medicine and clinical research.<sup>3</sup> Her takeaways from that workshop were that ableism is "pervasive" in research, and people with disabilities are often excluded from NIH studies with "little scientific justification." In Cernich's estimation, "people with disabilities need to be part of research teams to broaden perspective and ensure relevance of studies to the community."

# Philanthropy

As philanthropy can be beneficial to scientists' funding, Imparato invited Emily Harris, executive director of the Disability and Philanthropy Forum, to give an overview of where the sector was on disrupting ableism. The biggest issue, up until recently, Harris said, was that most foundations ignored ableism and ignored "that so many people that they serve are

<sup>&</sup>lt;sup>1</sup> For more information, see https://www.healthaffairs.org/doi/10.1377/hlthaff. 2022.00475.

 $<sup>^2\,</sup>Section$  508 of the Rehabilitation Act of 1973, available at https://www.section508.gov/.

<sup>&</sup>lt;sup>3</sup> For more information, see https://www.nichd.nih.gov/about/meetings/2023/042723.

disabled.... We have to recognize that our sector really has been behind." Her group was recently able to examine 2019 grant data from Candid<sup>4</sup> and learned that "what the disability community has been saying all along is absolutely right": only 2 percent of U.S. foundation funding went to disability issues that year. The lion's share of that 2 percent was only for services and supports, a category that is more based on the idea of disabled people needing protection, rather than looking at agency of people with disabilities, Harris said. "In fact, strikingly, we found that only 1 penny of every 10 dollars of U.S. foundation funding ... went to disability rights and justice funding, aiming at dismantling barriers for full participation and promoting systems change."

There has been some progress since 2019, Harris said. One of the tools her group has created is a disability-inclusive pledge that includes eight areas for growth, and they now have 78 philanthropic organizations signed on. "The important thing is that CEOs are challenging their peers to lead for inclusion, and we're starting to see results." Specific actions she has seen foundations take include training on inclusion for boards and staff, and asking about accommodations for events for everyone to fully participate. "These are very low-bar places to start, and over time, we are seeing growth to more complex actions," she said, adding they are seeing foundations starting to move money through disability-led funding groups, including the Disability Inclusion Fund at Borealis. Foundations are also recognizing that disability is part of every issue, Harris said. One research funder is now asking grantees to report how many disabled scientists are on panels or projects, "signaling to grantees that they care about that," she said.

#### **Private Sector**

Leadership has an important job when setting expectations and integrating accessibility in the private sector, said Angela Lean, senior business program lead of Accessible Employee Experience at Microsoft. The company's CEO, Satya Nadella, is a parent of a person with a disability, and has "done a wonderful job of actually tying accessibility to our overall corporate mandate" of empowering organizations and people to do more, Lean said. "I think assistive technology does that for people with

<sup>&</sup>lt;sup>4</sup> For more information, see https://candid.org/.

<sup>&</sup>lt;sup>5</sup> For more information, see https://borealisphilanthropy.org/disability-inclusion-fund/.

disabilities," she said, and that mandate and Nadella's leadership "gives us a lot of wind at our back at the accessibility office in terms of what we are trying to achieve at Microsoft and beyond."

Expanding workplace accessibility is also a business opportunity for Microsoft and their customers, Lean said, noting a recent statistic from the World Health Organization that a billion people, or 15 percent of the global population, have a disability: "Those are our customers," she said, adding that while opportunity was different in the academic world, it is about "making yourself more relevant to more people."

Accessibility is a fundamental right *and* innovation, Lean said, and her office works to take lived experience and apply it to product development. They have information desks that take feedback from both customers and employees about how the technology is or is not working for them. "We really invoke the notion of design for one and extend it to all," Lean said, explaining feedback about PowerPoint from colleagues with low vision is applied to the overall roadmap, not just an immediate fix.

# Scientific Publishing and Universities

Holden Thorp, editor-in-chief of *Science*, said journal accessibility had improved since the days of "printed materials that were placed in heavy, hard-bound journals on high shelves," but additional changes would have to contend with the current structure of their academic publishing industry. "The good news is you don't have to convince that many entities to continue to make improvements; the bad news is no individual journal can do it on their own," he said, adding "*Science* has a powerful voice and we love to use it anytime we can, to make journal articles more accessible."

He is concerned about how open-access licenses allow for altered copies of papers that could be even more inaccessible than official versions, as well as the pressure of focusing on the quantity of academic publishing. "What do we do to ... account for the fact that not everybody has the opportunity to create research at the same rate as everybody else?" he asked. "The journals can't fix that problem on their own, but if we are really going to dismantle ableism, it has to be the case."

Barbara Snyder, president of the Association of American Universities, noted that universities have lots of organizations focused on compliance. "There is nothing wrong with that, but of course, it doesn't get you where you need to go," Snyder said. While universities have disability and inclusion offices, often students, faculty, and staff still have to advocate for

themselves while navigating the campus, she said. "That can be daunting and exhausting."

Snyder also echoed a comment made by Cernich, saying universities not only had the challenge of not enough researchers with disabilities bringing their perspective, but the focus of research "on a small swath of the population, on mostly white men, for the longest time." The goal for research and education, she said, should be "to make sure that everybody is at the table who needs to be at the table. I think that is not happening quite yet, but [it] is starting to happen."

#### **Action Items**

Imparato asked the panel to think about what action steps their industry, sector, or company could take that would make a difference in terms of disrupting ableism. The most important thing, Cernich said, is that anything done needs to start with the disability community, and it cannot be solely one person or group of people representing everyone with a disability. Changing the mindset in NIH is hard because it is a medical model organization, she added, and getting to full participation for disabled scientists means shifting the conversation toward a social model. "I think the only way to do that is to meaningfully engage with the organizations and people who are wanting to be a part of the STEM community and are finding barriers, and then asking them how do we work with you to overcome those?" It cannot be unilateral, but changes have to start with NIH's own employees and intramural researchers. "If we are not doing it internally, how can we expect universities to do it?" Educating extramural scientists and adjusting policies for grants may be a way to integrate changes more widely. "They are receiving federal funds. How are we bringing them into the community to understand that those indirect costs have to support some of this?" she asked.

Harris said foundations need to move away from their tendency to compartmentalize, instead recognizing the overlap and connecting disability explicitly to their funding focuses. "If you fund climate justice work, who do you think is most impacted by climate change? If you are funding STEM education, who do you think are the students with the most potential but the least resources? If you want to break the school-to-prison pipeline, who do you think are the first children to be caught in that system?" Taking any funding issue and asking disabled people how they would solve those challenges will allow funders to begin to see the connections, as well as fund solutions that are going to be better for everyone.

Presidents and chancellors need to be talking more about disability, both on campus and in their broader community, Snyder said, because that is a signal to the university that this is an important issue. She also suggested universities need to consider universal design not just for physical spaces but for curriculum as well.

Thorp said STEM needs to move away from the idea of "doing more research is always the best possible thing. For the last 80 years in this country, we built up as the goal, to have a big lab, a high h-index, and a lot of citations, and a lot of grant money. As a result, everybody is so busy pedaling these bicycles that nobody is stopping to think about the people that are actually there," he said. And "almost every bad thing about STEM is a readout of the fact that we are trying to do too much science instead of doing better science," including not valuing people who cannot churn out a lot of science, underpaying graduate students and postdocs, and overworking administrators. As editor-in-chief, he can keep talking and writing about this problem, but "we need more people to have the courage to say that."

Lean identified three areas that she thinks are leading actions in the private sector that are also applicable to academia. First, inclusive hiring and representation on panels and on grant decisions. This would include setting up employees with disabilities for success in the onboarding process. Second, tracking data to inform investments and business decisions that improve accessibility. "Self-ID is a big movement in [the] tech industry," she said, because it gives the employees an opportunity to say broadly if they have a disability or not. "It is not disclosure, but about recognition of who in the organization has a disability." Third, Lean suggested creating documents and content with accessibility in mind, including Microsoft's accessibility checker. "That's a very easy actionable thing for folks to do on a daily basis," and it has huge implications.

#### What Should Be Measured?

Mahadeo Sukhai, vice president of research and international affairs and chief accessibility officer of the Canadian National Institute for the Blind, asked the panel's thoughts about how campuses and workplaces can encourage measuring inclusion, and what should they be measuring?

While "very important things happen on our campuses that cannot be measured," Snyder said, it is important to measure things that you care about, and to do so accurately. She was interested in datasets on selfidentified disabilities of students, faculty, and staff, but also in the alumni population. On the research front, Snyder thought it was important to track the number of researchers, including postdocs and graduate students, with disabilities, the topics they were researching, and how they were doing compared to other populations and the university population at large. University offices of accessibility or similar groups keep track of how many people they serve each year, she said, but "I don't know if they track their satisfaction." "I would like to know how … the people they have served think about the service they got and whether it was effective in allowing them to do their work to the best of their potential, whether they are a student, employee, faculty member, you name it."

# How to Approach Administrators or Leaders?

Ann Jeffers, professor of civil and environmental engineering at the University of Michigan, said Barbara Snyder's advice was aimed toward administrators, but the "more likely scenario" is that people with disabilities will have to bring problems to the attention of administration. Jeffers asked what her suggestions would be for a group of faculty who wanted to sell the university administration on the idea of becoming a more inclusive campus from the perspective of disability.

"I hope that you would not have to sell" the importance of everyone taking advantage of what a university has to offer, Snyder said. "On the other hand, I know that there are competing priorities, and administrators have to make difficult decisions sometimes." She suggested starting the conversation anyway, bringing specific ideas about how to resolve the problems they are seeing and be willing to engage in a back-and-forth dialogue. Identifying the benefits for the university is also important, she said. "I hope that each one of our campuses would say ... we want to be the most inclusive campus in the country, in the world."

Thorp, who previously served as a university chancellor and provost, said his more disruptive answer is "campus activism does work." "I do agree with Barbara that it is good to start off developing a relationship with the administrators," he said. But administrators go from crisis to crisis, he added, distracting them from issues like a more inclusive campus. "Unfortunately, that means you may need to create a crisis in order to get them to work on this."

"Making it come to life" for people you are talking to is really important anywhere you work, Lean said. When people she works with at Microsoft think accessibility is a niche issue, she related the fact that her difference—not being able to use one arm—could happen temporarily or intermittently to anyone, for instance, if they broke their arm or needed to carry a baby. "I cannot tell you the power of walking into an executive team meeting with some of our accessible products, and when they see the innovation and they see the relevancy of what their products can do for people who have differences, it's a very powerful moment," she said. She often starts conversations asking what is similar about a pair of shoes and a diaper. It is hard to use one hand to put a diaper on a child or tie your own shoe. People often told her they did not think about it that way. "Just having that moment of relation or connection is often helpful."

At the end of the panel, Imparato summarized that involvement of disabled people in the workforce at every level was crucial for full participation in STEM. "If we start by listening to disabled people and [we] hired disabled people, we have this conversation at the highest levels of our sectors and institutions and we fund accessibility, we'll have better science," he said.

#### MOVING BEYOND COMPLIANCE

Logan Gin, a member of the National Academies' Beyond Compliance: Promoting the Success of People with Disabilities in the STEM Workforce Committee and assistant director for STEM education at the Sheridan Center for Teaching and Learning at Brown University, moderated a panel on moving beyond compliance in the workforce.

# How the Americans with Disabilities Act (ADA) Has Changed

Gin began the discussion by asking panelists to explain why the Americans with Disabilities Act (ADA)<sup>6</sup> was created and how it has evolved through 2023. Jasmine Harris, professor of law at the University of Pennsylvania, said the ADA was created to deal with a lack of legal protections, or as one of the drafters of the law, Robert Burgdorf, described it, "a response to an appalling problem: widespread, systemic inhumane treatment and discrimination against people with disabilities." The absence of legal protections and deeply entrenched social stigma equating disability with functional incapacity "resulted in the historic segregation of people with disabilities from all facets of life," Harris added, including public

 $<sup>^6</sup>$  42 USC 12101, available at https://uscode.house.gov/browse/prelim@title42/chapter126&edition=prelim.

education, the workforce, and in some places, the right to vote, marry, or have children.

The ADA prohibits discrimination across different areas, including public services and employment, but it is unique among other civil rights laws in that it requires proof of being protected by that law in the first place, Harris added. "To fall within the ADA's protection, you have to prove that you meet the definition of disability within the law." Not everyone with a disability automatically meets the definition, and as a result, that definition has been litigated over and over again, she said. "Basically, the first 18 years of the ADA was spent in court trying to ... have judges interpret who's in and who's out in terms of disability."

Aaron Konopasky, senior attorney-advisor at the U.S. Equal Employment Opportunity Commission (EEOC), said that over the many years of his career, he has learned that "nobody learns anything about the ADA by talking about that definition," and he offered the historical perspective that prior to 2009, it was "relatively hard to have disability" under the ADA. What happened, Harris and Konopasky explained, was that Congress amended the law to broaden the definition of disability, making it more inclusive than what had been litigated through the U.S. courts.

"It's a little bit difficult to overstate the degree to which it changed," Konopasky said, likening the current understanding of disability under the law as being closer to the category of having a medical condition. "It's true that you have to ... meet some sort of threshold in terms of the kinds of symptoms ... but especially if you're an employer, it may not be worth your while to spend too much time thinking about whether or not a particular person meets the definition of disability." If they are disclosing disability and asking for a reasonable accommodation, "most likely their condition is going to meet the definition."

This has had the biggest effect in the mental health area, Konopasky said. The law protects against discrimination or disparate treatment because of disability. In the workplace, he said, this often is a result of negative stereotypes of disabled people, and assumptions about safety and competence when considering them for a job. "ADA says you can't do that," Konopasky said. "You have to look at the individual person." There are also prohibitions against harassment and physical threats, as well as protections that limit an employer's ability to ask for medical information, and keep confidential what they do have, he noted.

But the "heart" of the ADA is reasonable accommodations, Konopasky said. When discussing the workplace, he likes to start with a thought exer-

cise of asking people how they would react if they showed up to a new job and found their desk was 12 feet high. "You might reasonably say, Well, wait a minute.... I don't fit into that desk ... and that's really the experience that some people with disabilities have every day." Historically, employers have been allowed to choose employees who "fit" into a job in this way, he said. What is innovative about the ADA is that "at least in some respects, the employer is now obligated to fit the job to the person." Working from home, a quiet office space, a braille printer are all examples of reasonable accommodations under the ADA, but they can be very individualized, he said. The goal is to work with the employee to try to figure out what would help them do the job.

Contrary to popular opinion, the ADA does have limitations, he added, including if the accommodation would present a hardship to the company, but that is a high bar to clear. "It's not the supervisor just being stubborn, that's not good enough. It has to be something that interferes with your ability to do business and makes accomplishing the work goals difficult or impossible." Large academic institutions with well-funded endowments are unlikely to meet this test, he said. The ADA also does not require lowering production standards or the quality of work.

Harris agreed that individualization is important for workplaces complying with the ADA through accommodations. "A defense that sometimes comes up is, 'We've never done this before,'" she said. "The fact that you didn't do it before means that you didn't encounter this particular individual," and the law still requires a response.

# Americans with Disabilities Act in Higher Education Employment

The ADA does not ensure that everything has been implemented perfectly, Cathie Axe, executive director of Student Disability Services at Johns Hopkins University, said. "That's going to take work as institutions look at where our potential barriers [are] and how can we think ahead and plan for employees with disabilities."

Higher education has changed as more students with disabilities are making it to college and beyond, Axe said, because of better support systems, and a greater understanding of the social model of disability. But COVID-19 highlighted the barriers and how university structures themselves have negatively affected people with disabilities. "For years and years within higher education we had been saying certain things weren't possible," Axe said. "We saw that when needed, there were all

these changes that could happen quite rapidly and quite effectively." She hoped that part of the discussion rethinks traditional workplaces and how higher education is structured, "so that things happen more readily and are seamless for people," instead of working tremendously hard to get accommodations.

## Common Issues with Employers and Employees

Gin asked the panelists the common conflicts they saw between employees and employers. Fear of the unknown is a big issue, Harris said, and when employers are not well informed or comfortable with the accommodation process, they can become very reactive. Preplanning and understanding their role, through resources like the Job Accommodation Network, can help an employer be much more comfortable when a request comes in, she said. Gin commented that accommodations by design pushes against the common human resources framework of treating everyone the same way. "Making exceptions, treating people differently to get what they need, that's an idea that people aren't always immediately comfortable with," she said, giving examples of large employers talking about telework as a moral failing. Harris noted that the rebuttal to the idea of "fairness" when considering accommodations is "the workplace itself" was designed with able-bodied, neurotypical individuals in mind. "The ADA and Congress understood that the form of discrimination may look different and accounted for that," she said.

The main mechanism for enforcing the ADA on employment and accommodations is still a lawsuit, Konopasky noted. "Obviously it's not a first choice because it requires a lot of work and intersection with the legal system," he said. "But people are perfectly within their rights to file charges of discrimination with the EEOC."

Workplace rights also include a back-and-forth discussion with the employee about what is going to be effective for them, Axe said. "You don't have to get the accommodation that you request, but it has to be something that is effective," she said. It also encourages employers to gather more information about what is considered reasonable. "No one wants to make those decisions on their own.... Multiple perspectives will help us to land in the right place." Axe also tells managers to consider it a process, with the ability to revisit if the initial plan is not working. "We also can admit if something

<sup>&</sup>lt;sup>7</sup> For more information, see https://askjan.org/.

has had an impact that we didn't anticipate," she said. "I think that can help everyone to kind of relax a little bit about the process."

Delays or additional paperwork to gain the accommodation can be just as discriminatory as an outright denial, Konopasky said. "Employers shouldn't think they can get away with just sitting on it forever." Paperwork demands are trickier, he noted. "Generally speaking, employers are entitled to less medical documentation than they think they are," but basic documentation for more invisible disabilities may make sense. That being said, Konopasky added, "it's not unheard of that the employer would use requesting medical information as a way to punish the person and to delay the whole process," and that goes to the privacy part of the law.

#### What Is Next for the Americans with Disabilities Act?

Gin asked the panelists what they expected the next 30 years of the ADA to look like, especially for disability in the workplace and moving beyond compliance. Axe pointed out the need to ensure workplaces have a culture that makes an accommodation request easier and allows people to be honest that they need something without being singled out. Part of that effort is all employees' active participation in the workplace to combat stereotypical reactions or traditional kinds of approaches. "That's the number one thing I hear [from employees] ... what they overheard in the workplace has made it very difficult for them to come forward," she said, and delaying the request not only makes it difficult for the individual but affects the employer or school as well.

Technological changes and wider adoption of telework will have a positive effect on how the ADA works in practice, Konopasky said. "As technology continues to develop, there will be more and more solutions to particular issues that people face." Harris added that employers must take the opportunity to use disability to rethink the workplace and be proactive instead of reactive to requests. Instead of an employer dealing with 20 individual requests for a sit/stand desk for those with carpel tunnel syndrome, they could be proactive and redesign the workplace so everyone gets a sit-stand desk.

#### WORKPLACE EXPERIENCES

Dave Caudel, associate director of the Frist Center for Autism and Innovation at Vanderbilt University, opened the discussion on workplace experiences by asking panelists to describe a welcoming experience they have had at work.

Amy Bower, senior scientist at Woods Hole Oceanographic Institution, said her workplace had been very accommodating and "extremely generous in providing reasonable accommodations for my vision loss," but she paused when considering if it was welcoming. "The almost minuscule number of people with disabilities at the institution means that I'm a superminority," she said. "Just even the lack of community is kind of lonely, to put it frankly." She also noted that her institution had not been "openly advertising their willingness" to provide accommodations to the entire community.

Flexibility in accommodations in her current role has been important to Meenakshi Das, a software engineer at Microsoft. As a person who has a stutter, speaking—especially for long periods—can be challenging, so she uses online chat functions as an accommodation. It is free and widely used by everyone in the company, but at other times, she does not want to use this tool. "Just because I stutter, that doesn't mean I don't have a voice."

A welcoming workplace begins at the front end of the hiring process, said Susanne M. Bruyère, principal investigator and co-project director of the Employer Assistance and Resource Network (EARN).<sup>8</sup> Her research has shown that people are far more likely to apply to a job if the company's website and career offerings signal they want a diversity of abilities. This may include seeing people like themselves on the website, information about accommodations on career pages, and affirmative hiring programs for neurodiverse people.

"Providing accommodations is basic; that is complying with the law," noted Anupa Iyer Geevarghese, chief of staff of the Office of Disability Employment Policy at the U.S. Department of Labor. "A welcoming workplace is taking it to the next step," she said, adding that another way to have a welcoming workplace is creating an employee resource group for people with disabilities and then actually leveraging that group "to feed into the work that you do." Research by the ODEP funded Job Accommodation Network has shown that a majority of accommodations cost nothing or less than \$300.

As an autistic individual, Caudel says, he has had a variety of jobs that have not been particularly welcoming or accommodating, and "as a consequence, I really struggled." His most welcoming workplace environment has been his current job, where he has worked for the last 10 years, and that has "made all the difference." A welcoming workplace can be beneficial

<sup>&</sup>lt;sup>8</sup> For more information, see https://askearn.org/.

to the institution as well: "We all have our own needs and if people can be met with those needs, you can get a lot of real quality work out of us."

# Challenges in the Workplace

Making even small changes in your institution can be exceptionally difficult if it does not become part of the wider culture, Bower said. For the past 4 years, she sat on an administrative council that was a very intensive work group with a lot of information exchange during the meetings. "I had to struggle for years to insist that they add alt text to the images in the PowerPoint presentations, and it got extremely tiresome," she related. Her fellow council members were "all extremely well intentioned, but it did not become part of the culture" or expected meeting behavior, despite multiple attempts and even the institution's president insisting presentations would be provided in advance. It was not really resolved, Bower said. "After 4 years I was glad to get off this council."

Stigma can also influence the interviewing process, Das said. During interviews for an internship, she thought she answered well, but she did not get the job. "I don't really know the real reason ... but the feeling I got from the whole process was that they felt that I was too slow for them" and associated her stutter with low intelligence. Caudel agreed, saying a common shortcut is assuming intelligence based on the ability to talk. "Some very, very intelligent people struggle to string a simple sentence together," he said. "Mena is a software engineer at Microsoft.... She has a brain that can do complex things. So, if she takes a minute to put the sentence together ... it's not a fair comparison on what her capabilities are."

Advocating for oneself can lead to resolution of workplace problems, Caudel said, if managers and employers are willing to listen. He described a situation in which he coached a young woman with autism whose desk was next to a water cooler, making it difficult for her to focus on her job. Her initial request to move to a different desk was denied, but she was moved after she told her boss that her neurological condition meant she would do a better job if she was away from the water cooler. "If it's something that could have a potentially positive impact on their job, as much as humanly possible we should consider it," he said.

Geevarghese described a similar experience with changes she made to her work environment to account for people interrupting her, and her ADD (attention deficit disorder) making it hard to get back on track. It was early in her career, and she did not necessarily know what types of accommodation would work for her. She ended up borrowing an idea from the autistic community about using color-coded cards to identify her busyness and willingness to be interrupted. She discussed the idea with her boss, and aside from some reminders, it worked out for the most part. "The employee doesn't have to use any magical words," she said. "I said, I'm having a challenge doing X and that is related to my disability. Can we figure out how to make it work and what are some potential solutions?"

Bower said people without disabilities "ask for work accommodations all the time for all kinds of reasons ... and yet, if one has a disability, somehow there's this giant hesitation to do it ... for fear of some kind of negative feedback or being refused an accommodation." Recognizing that requests—and accommodations—were a part of nondisabled employees' experiences "helped me be a little less hesitant." Bruyère confirmed this from her own work: "What we hear often [is] that career advancement is stymied by people's hesitation to ask for those accommodations."

## What Can Employers Do?

Employers need to publicly and openly welcome applications from people with disabilities, Bower said, but they need to indicate their willingness to go beyond compliance and interpret reasonable accommodations in the broadest possible sense. They also need to avoid asking employees to do their accessibility testing, as there are professional organizations that do so, she said. For example, she uses a screen reader, but she should not have to test out all her organization's webpages. "I'm an oceanographer; I'm not a technology expert," she said. "My peers aren't being asked to do that kind of testing." Caudel agreed, adding that organizations should not rely on employees to "pull double duty," but they can encourage employees to reach out to suggest something if they notice something wrong or something that could be done better.

Complying with the law is step one, Geevarghese said. Employers must also include accessible technology from the start, from early stages to a full rollout, and make their workplaces mental health friendly and include accessibility in any DEI work they do. "Actions speak louder than words," Das added. "If you are marketing that you are a very inclusive place, your actions need to show that too. For example, if you want to hire more people with disabilities, but your job site is not accessible, it's of no use." Employers need to make sure they invest the time in making workplaces inclusive.

# CAREER ADVANCEMENT AND PROFESSIONAL DEVELOPMENT

In a separate panel, Caudel spoke with a variety of people about improving career advancement and professional development for people with disabilities. He asked panelists what programs and practices had a good approach to these areas, and what would they like to see.

Mariah Lynn Arral, NIH fellow and doctoral candidate at Carnegie Mellon University, identified mentorship programs started by disabled individuals as part of the DisabledInSTEM Twitter group as "you don't always find a mentor in your own program who is disabled." She also mentioned application assistance programs to discuss how to approach graduate school and other applications. "Both of those programs have done a fantastic job in not only facilitating keeping graduate students who are disabled in their programs, but also helping students [who are disabled] get into graduate programs." She herself started a peer mentoring group at Carnegie Mellon.

John Tschida, executive director of the Association of University Centers on Disabilities, is a "big fan" of employee affinity groups or similar setups, especially where there is strong buy-in from organizational leadership. A study by DisabilityIN¹⁰ found that the presence of three factors in the workplace, that is, an affinity group, disabled leadership, and C-suite buy-in, "was optimal for achieving both business outcomes and outcomes for the individual with a disability as well." A crucial part, he added, is how these affinity groups are being engaged in evaluating policies and formulating new ones. Companies must take advantage of existing disabled leaders in the organization, "both to show them opportunities for engagement and [to] help them serve as role models for success."

# Trainings for Workplace and Workforce

An estimated 20 million working-aged people are neurodivergent, said Ernie Dianastasis, CEO of The Precisionists, Inc., and about 15 million can do the types of office jobs and sustainable work that can create really successful careers. It is an untapped labor pool, he said, especially as the United States has millions of unfilled job openings. "The challenge actually becomes an incredible opportunity," he said, but it involves getting job can-

<sup>&</sup>lt;sup>9</sup> For information on DisabledInSTEM, see https://disabledinstem.wordpress.com/.

<sup>&</sup>lt;sup>10</sup> For more information, see https://disabilityin.org/.

didates ready for the workplace and the workplace educated on the strengths of neurodiverse employees. His organization has a training program for both the technical skills and the workplace skills for the job candidate, but also training for organizations on working with neurodiverse talent. "Employment is just one piece of the puzzle," but a key one, Dianastasis said. Sustainable employment often leads to other forms of independent living. "We have had countless examples of people seeing their confidence level going up," after stepping into careers, and wanting to live on their own, get drivers' licenses, and more, he said. "Other pieces of the puzzle start to come together if the employment piece is solved."

Caudel noted that more than 80 percent of people on the autism spectrum are unemployed or underemployed, even including people with bachelor's and graduate degrees. Arral said educating the workforce on disability literacy is key. She has given several talks and had plenty of conversations in her home department because a lot of organizations do not know even how to talk about disability. "It's something that is really needed across the board, because you can't make advancements for disabled people if [nondisabled] people don't even know who disabled people are and what rights they have," she said. Dianastasis agreed, saying, "One of the biggest mistakes we can make is [to] assume that everybody is at the same level of awareness and knowledge." In group settings he can be talking to people who have direct experience or they themselves are neurodiverse and people who have no knowledge or grounding.

# Strengths and Confidence

Dianastasis said that employers and any program that encourages professional development must highlight the strengths of the individual. "This applies whether you're neurodivergent or whether you're neurotypical," he said. "This is what the education system also needs to strive for all the time ... [to] figure out the strengths of each individual," and to figure out how to unlock that.

Arral said that this has made a difference in her career so far. She was fortunate to have a mom who did not agree with teachers who said Arral would not be able to hold down a job or live independently because she was autistic. "She had my back," she said, adding a lot of individuals who are on the spectrum do not have parents like that. "It's [an] important thing to think about that what support they have gotten throughout their life is also going to impact how they're successful in their job." She added that it needs

to be acknowledged that people who are open about their disabilities "will be judged differently, they will be evaluated differently." "A lot of times I hear people say, 'No, we're not going to do that, we don't judge people differently,' but we absolutely do. It's an unconscious bias we have." Focusing on the strengths mindset takes away from the negative effects of this bias.

Tschida agreed that a strength-based framework is going to have a "direct impact" on an individual's level of confidence. It also requires an employer to listen to the disabled employee about their strengths and understand that their institution may not have the competency in providing full development they thought they had. These strengths are different from person to person, Caudel added, and can work if teams are willing to become uncomfortable about how to best integrate the strengths of each team member. "I'm primarily a visual thinker … but it would be foolish to think that's the only way to get this job done."

## **Attending Conferences**

"This is a really hard question because it really depends on the disability, it depends on the person's needs, it depends on money," Arral said in response to a question about how conferences—and the professional development opportunities they represent—can be better facilitated for people with disabilities. She said she enjoys in-person conferences, as long as she self-moderates, but understands that others prefer and can really benefit from virtual conferences. For her, that means how hybrid conferences are organized is crucial. "We need to be very diligent ... that there is direct interaction designed for virtual attendees, so [that] they're actually getting what they're paying for," she said.

Tschida pointed out that plenty of information is available for conference organizers to best design conferences for all people. "This ground has been plowed by many disability organizations before you," he said, to ensure not just accessibility but the engagement and involvement of people with disabilities in the planning process and the programming. "Make sure that people with disabilities are seeing themselves on the dais and not just off in some disability-only group or room." Accounting for translation services for attendees who speak languages other than English as well as plain language for those with intellectual disabilities is increasingly crucial, he added. "It needs to be intentional and that needs to happen at the very beginning, not at the end when you realize you have forgotten something or forgot to the engage a key constituency."

# Reflections and Next Steps

#### IDEAS FOR ACTION ACROSS ALL WORKSHOP DAYS

Throughout the workshop series, committee members, panelists, and audience members made calls for change and suggestions for broad strategies and next steps in disrupting ableism in science, technology, engineering, and mathematics (STEM), including the following:

- Holden Thorp, editor-in-chief of Science, suggested a consensus study on these topics to be undertaken by the National Academies of Sciences, Engineering, and Medicine.
- In her closing remarks, Bonnielin Swenor, chair of the planning committee and director of the Johns Hopkins Disability Health Research Center, said there was an urgent need for funding for programming and training to combat ableism and to support disabled people in STEM.
- In her paper presentation, Jacquelyn Chini, associate professor of physics at the University of Central Florida, made several suggestions, including adopting disability status metrics across wider datasets, such as the Integrated Postsecondary Education Data System, or IPEDS, and the Survey of Graduate Students and Postdocs, or CSS, as well as a call for qualitative data about disabled people's experience in STEM (see Chapter 3).

- Sam Catherine Johnston and Luis Pérez, both from the postsecondary and workforce development office at CAST, offered a variety of ideas for curriculum and field research changes based on universal design (see Chapter 4).
- Kate Mittendorf, senior staff scientist at Vanderbilt University, made several suggestions in their paper presentation, including publicizing accommodation processes to all employees when they are introduced to the workplace and a workforce training model that moves away from the model of "access as gift" (see Chapter 7).
- Jae Kennedy, community and behavioral health professor at Washington State University, called for the National Institutes of Health, the U.S. National Science Foundation, and the "federal research enterprise" to lead the way on destignatizing disability and encouraging disclosure, even when accommodations are not needed or there is no identified discrimination.
- Wanda Díaz-Merced, an astronomer at the European Gravitational Observatory, said that the wider scientific community needed to make a dedicated investment to moving to multisensorial practices across scientific fields.

# U.S. NATIONAL SCIENCE FOUNDATION REFLECTIONS AND SOLICITATION

Christopher Atchison, program director for the Directorate for STEM Education at NSF and professor of geology and science education at the University of Cincinnati, opened the reflections and next steps dialogue by pointing out that the discussion and communities coming together at the workshop was already having an effect on federal agencies, on professional societies, and throughout academia. After the first day of discussions, many participants had told him they were more motivated than overwhelmed.

"I hope you still feel the same, but regardless, if you're overwhelmed or you're motivated, I still want you to pick the one thing, what is the one thing you learned from this convening, and do your best to continue pushing for that one thing," he said, whether it is in the classroom, in policy development, in training, or elsewhere. He noted that much of what has been said during the workshop series has been shared for decades; it is time for bringing that to a wider audience. "I want you all to think about how can we reach and connect with those who are not here."

## Appendix A

## Agendas

## DISRUPTING ABLEISM AND ADVANCING STEM: A NATIONAL LEADERSHIP SUMMIT

### Monday, June 5, 2023

## 11:00– 11:10 AM ET

## Welcome from the Planning Committee Chair

 Bonnie Swenor, PhD, Director, Johns Hopkins Disability Health Research Center

## 11:10-11:45 AM ET

## Towards Disrupting Ableism and Advancing STEM

- Bonnie Swenor, PhD, Director, Johns Hopkins Disability Health Research Center
- Marcia McNutt, PhD, President, National Academy of Sciences (NAS)
- Karen Marrongelle, PhD, Chief Operating Officer, U.S. National Science Foundation (NSF)

## 11:45– The Intersection of Disability Identity, Equity, and 12:45 PM ET STEM

#### Moderator:

 Mona Minkara, PhD, Assistant Professor, Department of Bioengineering Northeastern University

#### Panelists:

- Wanda Díaz-Merced, PhD, Astronomer, European Gravitational Wave Observatory (EGO)
- Anjali Forber-Pratt, PhD, Director, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Cassandra McCall, PhD, Assistant Professor of Engineering Education, Utah State University

## 12:45– 2:00 PM ET

**Lunch** – Located at the Keck Atrium (3rd Floor)

## 2:00– 2:45 PM ET

## Describing Disability: Language and Models

#### Moderator:

 Michele Cooke, Professor of Geosciences, University of Massachusetts, Amherst

#### Panelists:

- Jacquelyn Chini, PhD, Associate Professor and Undergraduate Program Associate Director, Department of Physics, University of Central Florida
- Vivian Cheung, MD, Frederick G. L. Huetwell Professor of Pediatric Research, Life Sciences Institute, University of Michigan School of Medicine
- Jae Kennedy, PhD, Chair, Department of Health Policy and Administration, Washington State University
- Mahadeo Sukhai, PhD, Vice President Research and International Affairs and Chief Accessibility Officer, ARIA Team (Accessibility, Research and International Affairs) Canadian National Institute for the Blind (CNIB)

2:45– *Break* 3:15 PM ET

## 3:15– 4:15 PM ET

## The Complexity of Workplace Ecosystems

#### Moderator:

 Andrew Imparato, JD, Executive Director, Disability Rights California

#### Panelists:

- Alison Cernich, PhD, Deputy Director of National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH)
- Emily Harris, MA, Executive Director, Disability and Philanthropy Forum
- Angela Lean, MBA, Senior Business Program Lead, Accessible Employee Experience at Microsoft
- Barbara R. Snyder, JD, President, Association of American Universities
- Holden Thorp, PhD, Editor-in-Chief, Science

## 4:15– 4:30 PM ET

## Summit Reflection and Overview of Upcoming Series Sessions

- Christopher Atchison, PhD, Program Director, Directorate for STEM Education (EDU), U.S. National Science Foundation (NSF)
- Mark H. Leddy, PhD, MS, Lead Program Director, Directorate for STEM Education (EDU), U.S.
   National Science Foundation (NSF)
- Bonnie Swenor, PhD, Director, Johns Hopkins Disability Health Research Center

## 4:30 PM ET ADJOURN

## DISRUPTING ABLEISM AND ADVANCING STEM: CREATING DISABILITY-INCLUSIVE WORKFORCES AND WORKPLACES

Wednesday, June 7, 2023

## 12:00– 12:05 PM ET

## Welcome from the Planning Committee Member

 Jordan Rodriguez, MS, Civil Engineer in Training, Phoenix DPG Co-Lead, Stantec

## 12:05-12:45 PM ET

## Workplace Experiences and Advice from and for Decision-Makers

Moderator:

- David Caudel, PhD, Associate Director, Frist Center for Autism and Innovation, Vanderbilt University

  Panelists:
- Amy Bower, PhD, Senior Scientist, Physical Oceanography, Woods Hole Oceanographic Institution
- Susanne M. Bruyère, PhD, CRC, Academic Director, K. Lisa Yang and Hock E. Tan Institute on Employment and Disability and Principal Investigator and Co-Project Director, EARN
- Meenakshi Das, MS, Software Engineer, Microsoft
- Anupa Iyer Geevarghese, JD, Chief of Staff, Office of Disability Employment Policy (ODEP), U.S. Department of Labor

## 12:45– 1:15 PM ET

### Break

## 1:15– 2:00 PM ET

## Moving Beyond Compliance with Legal and Employment Policies and Procedures

Moderator:

 Logan Gin, PhD, Assistant Director of STEM Education, Sheridan Center for Teaching and Learning, Brown University

#### Panelists:

 Cathie Axe, MEd, Executive Director, Student Disability Services (SDS), Johns Hopkins University

- Jasmine Harris, JD, Professor of Law, University of Pennsylvania
- Aaron Konopasky, JD, PhD, Senior Attorney-Advisor, Office of Legal Counsel, U.S. Equal Employment Opportunity Commission (EEOC)

## 2:00– 2:45 PM ET

## Supporting Worker Professional Development and Career Advancement

Moderator:

- David Caudel, PhD, Associate Director, Frist Center for Autism and Innovation Vanderbilt University

  Panelists:
- Ernie Dianastasis, MBA, Founder and Chief Executive Officer, The Precisionists, Inc. (TPI)
- John Tschida, MPP, Executive Director, Association of University Centers on Disabilities (AUCD)
- Mariah Lynn Arral, BS, NIH National Research Service Award F31 Fellow and Doctoral Candidate, Department of Chemical Engineering, Carnegie Mellon University

## 2:45– 3:00 PM ET

## Reflection and Overview of Upcoming Series Sessions

- Christopher Atchison, PhD, Program Director,
  Directorate for STEM Education (EDU), Division
  for Equity of Excellence in STEM (EES), U.S.
  National Science Foundation (NSF) and Professor,
  School of Education and Department of Geology,
  University of Cincinnati
- Mark H. Leddy, PhD, MS, Lead Program Director, Division of Equity for Excellence in STEM and the Directorate for STEM Education (EDU), U.S. National Science Foundation (NSF)
- Jordan Rodriguez, MS, Civil Engineer in Training, Phoenix DPG Co-Lead Stantec

## 3:00 PM ET ADJOURN

## DISRUPTING ABLEISM AND ADVANCING STEM: FOSTERING EFFECTIVE MENTORSHIP IN THE STEM ECOSYSTEM

Tuesday, June 13, 2023

## 12:00– 12:05 PM ET

## Welcome from the Planning Committee Member

 Bonnielin Swenor, PhD, MPH, Director, Johns Hopkins Disability Health Research Center

## 12:05– 12:45 PM ET

## The Role of Mentorship in Disrupting Ableism and Advancing STEM

Moderator:

 Rupa Sheth Valdez, PhD, Associate Director, Department of Public Health Sciences and the Department of Systems and Information Engineering, University of Virginia

## Paper Presenters:

- Melissa McDaniels, PhD, Scientist and Associate Executive Director, Center for the Improvement of Mentored Experiences in Research (CIMER), University of Wisconsin, Madison
- Edmund Asiedu, MPA, Co-Chair, National Disability Mentoring Coalition (NDMC)

## 12:45– 1:30 PM ET

## Effective Mentorship Relationships: Fireside Chats Moderator:

 Michele Cooke, PhD, Professor, Department of Earth, Geographic and Climate Sciences, University of Massachusetts, Amherst

## Mentorship Pair #1:

- Hoby Wedler, PhD, Founding Partner/CEO, Wedland Group
- Dean J. Tantillo, PhD, Professor Department of Chemistry, University of California, Davis

## Mentorship Pair #2:

 Raja S. Kushalnagar, JD, LLM, PhD, Professor and Director of the Information Technology Undergraduate Program and Accessible Human-Centered Computing Graduate Program, Gallaudet University

 Matthew Seita, PhD, Recent Graduate, Department of Computing and Information Sciences, Rochester Institute of Technology

## Mentorship Group #3:

- Kristen Shinohara, PhD, Assistant Professor, School of Information, Rochester Institute of Technology
- Loam Shin, Undergraduate Student and Research Assistant, Center for Accessibility and Inclusion, Rochester Institute of Technology
- Michelle Olson, BS, Master's Student, School of Information, Golisano College of Computing and Information Sciences, Rochester Institute of Technology

### 1:30-2:00 PM ET

#### Break

## 2:00– 2:45 PM ET

## Programs to Foster Effective Mutual Mentorships Among Disabled Individuals

#### Moderator:

 Logan Gin, PhD, Assistant Director of STEM Education, Sheridan Center for Teaching and Learning, Brown University

#### Panelists:

- Erica Avery, PhD, Recent Graduate, Department of Physiology, Johns Hopkins University
- Ana Caicedo, PhD, Professor of Biology, University of Massachusetts Amherst and Co-Director, The Mind Hears
- Alyssa Paparella, BA, PhD Candidate, Cancer and Cell Biology PhD Program and Center for Precision Environmental Health, Baylor College of Medicine and Founder, DisabledInSTEM

Edward O. Manyibe, PhD, CRC, Capacity
Building Director and Research Associate Professor,
Rehabilitation Research and Training Center
(RRTC) on Research and Capacity Building for
Minority Entities, Langston University

## 2:45– 3:00 PM ET

## Reflections and Overview of Upcoming Series Sessions

- Christopher Atchison, PhD, Program Director,
  Directorate for STEM Education (EDU), Division
  for Equity of Excellence in STEM (EES), U.S.
  National Science Foundation (NSF) and Professor,
  School of Education and Department of Geology,
  University of Cincinnati
- Bonnielin Swenor, PhD, MPH, Director, Johns Hopkins Disability Health Research Center

## 3:00 PM ET ADJOURN

## DISRUPTING ABLEISM AND ADVANCING STEM: CULTIVATING ACCESSIBLE EDUCATIONAL PATHWAYS AND SPACES

### Thursday, June 15, 2023

## 12:00– 12:05 PM ET

## Welcome from the Planning Committee Member

 Emily Ackerman, PhD, Postdoctoral Researcher, Lahav Lab, Department of Systems Biology, Harvard Medical School

## 12:05-12:35 PM ET

## Changing Mindsets: Systems, Policies, and Programs Moderator:

 Emily Ackerman, PhD, Postdoctoral Researcher, Lahav Lab, Department of Systems Biology, Harvard Medical School

#### Panelists:

- Yvette E. Pearson, PhD, Vice President, Office of Diversity, Equity, and Inclusion, University of Texas, Dallas
- Lisa Meeks, PhD, Clinical Associate Professor, University of Michigan and Executive Director, DocsWith Disabilities Initiative

## 12:35– 1:15 PM ET

## Creating Disability Friendly Inclusive Accessible Spaces in Higher Education

#### Moderator:

 David Caudel, PhD, Associate Director, Frist Center for Autism and Innovation, Vanderbilt University

#### Paper Presenters:

- Sam Catherine Johnston, EdD, Chief, Postsecondary and Workforce Development Office, CAST
- Luis Pérez, PhD, Disability and Digital Inclusion Lead, Postsecondary and Workforce Development Office, CAST

#### Reflections:

 Jacquelyn Chini, PhD, Associate Professor and Undergraduate Program Associate Director, Department of Physics, University of Central Florida

- · Bradley Duerstock, PhD, Professor of Engineering Practice, Weldon School of Biomedical Engineering and School of Industrial Engineering, Purdue University
- Caroline Solomon, PhD, Director, School of Science, Technology, Accessibility, Mathematics, and Public Health (STAMP) and Professor of Biology, and Interim Program Director, Public Health Program, Gallaudet University

### 1:15-1:35 PM ET

## Break

## 1:35-2:15 PM ET

## Lived Experiences: Listening, Learning, and Acting Moderator:

- David Caudel, PhD, Associate Director, Frist Center for Autism and Innovation, Vanderbilt University Panelists:
- Megan Lynch, MSc, Master's Student, Graduate Group of Horticulture and Agronomy, University of California, Davis and Founder of UC Access Now
- Hari Srinivasan, BA, PhD Student, Department of Neuroscience and Former Visiting Fellow, Frist Center for Autism and Innovation, Vanderbilt University
- Stephanie Feola, PhD, Recent Graduate, Department of Chemistry, University of Florida and Postdoctoral Research Associate, University of Arkansas at Little Rock

#### 2:15-Transition to Work 2:45 PM ET

Moderator:

Emily Ackerman, PhD, Postdoctoral Researcher, Harvard Medical School

#### Panelists:

Laureen Summers, BA, Project Director, AAAS
 ISEED (Inclusive Ecosystems for Equity and
 Diversity) - Entry Point! Program, American
 Association for the Advancement of Science (AAAS)

- Kimberly J. Osmani, PhD, Senior Extension Associate, K. Lisa Yang and Hock E. Tan Institute on Employment and Disability (YTI), Cornell University
- Taryn M. Williams, MA, Assistant Secretary, Office of Disability Employment Policy (ODEP), U.S. Department of Labor

## 2:45– 3:00 PM ET

## Reflection and Overview of Upcoming Series Sessions

- Emily Ackerman, PhD, Postdoctoral Researcher, Lahav Lab, Department of Systems Biology, Harvard Medical School
- Christopher Atchison, PhD, Program Director,
  Directorate for STEM Education (EDU), Division
  for Equity of Excellence in STEM (EES), U.S.
  National Science Foundation (NSF) and Professor,
  School of Education and Department of Geology,
  University of Cincinnati
- Mark H. Leddy, PhD, MS, Lead Program Director, Division of Equity for Excellence in STEM and the Directorate for STEM Education (EDU), U.S. National Science Foundation (NSF)

## 3:00 PM ET ADJOURN

## DISRUPTING ABLEISM AND ADVANCING STEM: ROOTING OUT BIAS AND BARRIERS

### Friday, June 16, 2023

## 12:00- Welcome 12:05 PM ET

- Bonnielin Swenor, PhD, MPH, Director, Johns Hopkins Disability Health Research Center
- Christopher Atchison, PhD, Program Director,
  Directorate for STEM Education (EDU), Division
  for Equity of Excellence in STEM (EES), U.S.
  National Science Foundation (NSF) and Professor,
  School of Education and Department of Geology,
  University of Cincinnati
- Mark H. Leddy, PhD, MS, Lead Program Director, Division of Equity for Excellence in STEM and the Directorate for STEM Education (EDU), U.S. National Science Foundation (NSF)

## 12:05-12:35 PM ET

## Understanding Workplace and Workforce Barriers to Full Participation of People with Disabilities

Facilitator:

 Jordan Rodriguez, MS, Civil Engineer in Training, Phoenix DPG Co-Lead, Stantec

Paper Presenter:

 Kate Mittendorf, PhD, Senior Staff Scientist, Vanderbilt-Ingram Cancer Center, Vanderbilt University Medical Center

## 12:35– 1:15 PM ET

## Reflections on Solutions to Barriers Experienced by People with Disabilities in STEM

Co-Moderators:

- Anita Stone Marshall, PhD, Assistant Instructional Professor, Department of Geological Sciences, University of Florida
- Mona Minkara, PhD, Assistant Professor, Department of Bioengineering, Northeastern University

#### Panelists:

 Joey Ramp-Adams, Founder and CEO, Empower Ability Consulting (EAC), Inc.

- Rory Cooper, PhD, PLY, Assistant Vice Chancellor and Distinguished Professor, Research for STEM-Health Sciences Collaborations, Office of Senior Vice Chancellor for Research and Founding Director of Human Engineering Research Laboratories, University of Pittsburgh
- Sheri Byrne-Haber, JD, MBA, Author, "This Week In Accessibility" Medium Blog

## 1:15– 1:45 PM ET

#### Break

## 1:45– 2:30 PM ET

## Overcoming Bias and Stigma

#### Moderator:

 Emily Ackerman, PhD, Postdoctoral Researcher, Lahav Lab, Department of Systems Biology, Harvard Medical School

#### Panelists:

- Andrew Houtenville, PhD, Research Director, Institute on Disability and Professor of Economics, University of New Hampshire
- L. Miché Aaron, MS, Doctoral Student, Department of Earth and Planetary Sciences, Johns Hopkins University

## 2:30– 3:00 PM ET

## Series Synthesis and Reflection

 Bonnielin Swenor, PhD, MPH, Director, Johns Hopkins Disability Health Research Center

### 3:00 PM ET ADJOURN

## Appendix B

# Planning Committee Member and Speaker Biographies

#### WORKSHOP PLANNING COMMITTE

**Bonnielin K. Swenor** (*Chair*) is an associate professor at the Johns Hopkins Schools of Nursing, Medicine, and Public Health, and is the founder and director of the Johns Hopkins Disability Health Research Center, which aims to shift the paradigm from "living with a disability" to "thriving with a disability." Motivated by her personal experience with a visual disability, her work takes a data-driven approach to advancing health equity for people with disabilities and promoting disability inclusion in higher education, STEMM (science, technology, engineering, mathematics, and medicine), public health, and research.

Emily E. Ackerman is a postdoctoral researcher in the Systems Biology department at Harvard Medical School (HMS). Her work uses computational methods to understand p53 signaling dynamics. Her activism centers on the interaction between disability, technology, and education; she has published writings and spoken publicly on her identity as a disabled woman in computational science and the exclusion of disabled voices in STEMM fields. She holds a second HMS appointment as a disability advisor and serves on the Board of Directors of Future of Research, co-leading a project aimed at assessing and improving the labor conditions of academic workers.

**David D. Caudel** is the associate director of the Frist Center for Autism and Innovation at Vanderbilt University in Nashville, Tennessee. Diagnosed with Asperger's syndrome in 2009, Caudel is a neurodivergence advocate, speaking to a variety of organizations, including the United Nations and autism conferences internationally. He received his Ph.D. in physics at Vanderbilt University in 2017. He serves on the advisory committee for the Center for Discovery, Innovation, and Development (CDID) at Children's Specialized Hospital in New Jersey, the Clinical Advisory Panel on Intellectual and Developmental Disabilities for BlueCare Tennessee, the Vanderbilt University Diversity Council, and the All Access Inclusion Network, and is a founding member of the Vanderbilt Autism and Neurodiversity Alliance.

Michele L. Cooke is professor of geosciences at the University of Massachusetts (UMass) Amherst. She researches fault evolution in the Earth's crust using numerical models, laboratory experiments, and geophysical data. Cooke's collaborative research integrates these approaches to illuminate how faults grow, which helps constrain the hazard of damaging earthquakes. She is a fellow of the Geological Society of America and has served in leadership roles in several geoscience organizations as well as co-directing *The Mind Hears*, a blog by and for Deaf and Hard of Hearing academics. For her advocacy and outreach within the disabled community, she was awarded the UMass Amherst Distinguished Academic Outreach Teaching Award in 2010 and the International Association for Geoscience Diversity Inclusive Geoscience Education and Research Award in 2020.

**Logan Gin** is the assistant director for STEM Education in the Sheridan Center for Teaching and Learning at Brown University, where he works on initiatives related to STEM graduate student and postdoctoral teaching professional development. Prior to arriving at Brown, Gin was a U.S. National Science Foundation (NSF) graduate research fellow at Arizona State University and served as the program manager for an NSF S-STEM program focused on involving community college transfer students in undergraduate research. He holds a Ph.D. in biology from Arizona State University, where his dissertation work centered on the experiences of STEM students with disabilities in active learning classrooms, online courses, and laboratory and research environments.

**Andrew Imparato** is a disability rights lawyer and policy professional who has been working inside and outside government to advance policies and

practices to improve employment outcomes for people with disabilities for more than 30 years. His perspective is informed by his lived experience with bipolar disorder. He is the executive director of Disability Rights California, a \$44 million legal services and policy advocacy organization based in Sacramento with 26 offices across California. Since 2016, he has led the planning for four international summits on disability employment that have attracted participation from more than 40 countries. He has been an advisor on disability inclusion and accessibility to many large employers, including Walmart, Verizon, AT&T, Microsoft, IBM, Walgreens, and SAP.

Mona Minkara is an assistant professor in the Department of Bioengineering and an affiliate faculty in the Department of Chemistry and Chemical Biology at Northeastern University. She heads the COMBINE (Computational Modeling for BioInterface Engineering) Lab. Minkara uses computational methods to study biological interfaces at the atomic and molecular scales. Her current research examines pulmonary surfactant, the complex protein-lipid substance lining the alveoli. As a scientist who is Blind, she is committed to making science more accessible and inclusive through designing new tools for Blind scientists. Minkara received a B.A. from Wellesley College and a Ph.D. in chemistry from the University of Florida. Before joining the Northeastern University faculty, she held a postdoctoral appointment at the University of Minnesota Twin Cities Chemical Theory Center with a Ford Foundation Postdoctoral Fellowship.

Jordan Rodriguez is a civil engineer-in-training at Stantec based out of Phoenix, Arizona. He has 5 years of experience in the design, rehabilitation, and management of water, wastewater, and conveyance infrastructure. His disability experience is shaped by having Leber's hereditary optic neuropathy (LHON) and attention deficit hyperactivity disorder (ADHD). Outside of project work, he promotes accessibility and disability inclusion through co-leading internal document accessibility trainings, sitting on the Diversity, Equity, and Inclusion Committee of the Arizona Water Association and the Arizona Chapter of the American Public Works Association, as well as providing STEM career advice to local Blind and Low-Vision high school students.

**Anita Stone Marshall** is a lecturer and researcher in the Department of Geological Sciences at the University of Florida, Gainesville, and serves as the executive director of the International Association for Geoscience

Diversity. Her research focuses on improving access for people with disabilities in the geosciences with ongoing projects, including the GeoSPACE Accessible Planetary Geology field course, a Culture Change Project focusing on disabled geoscientists in professional settings, and the ASCEND research coordination network for creating more inclusive cultures in geoscience professional societies. She is actively involved in the diversity, equity, and inclusion community of geosciences, sharing her expertise and personal experience in STEM as a person with disabilities and a member of the Choctaw Nation of Oklahoma. Marshall has 17 years of undergraduate teaching experience designing inclusive and accessible courses in community colleges and R1 research institutions in a range of modalities—in-person, hybrid, and online. She received a B.S. in earth science, an M.S. in geology from the University of Arkansas, and a Ph.D. in geology from the University of South Florida.

Rupa Sheth Valdez is an associate professor at the University of Virginia. She merges engineering and social sciences to understand and address questions of health equity across home, community, and clinical spaces and has been supported by numerous federal agencies, including the National Institutes of Health (NIH), NSF, Agency for Healthcare Research and Quality, and U.S. Department of Agriculture. She recently testified before Congress on the topic of health equity for the disability community and received the Jack A. Kraft Innovator Award from the Human Factors and Ergonomics Society for her pioneering work in patient ergonomics. She holds numerous appointments, including as founder and president of the Blue Trunk Foundation, as a board member for the American Association of People with Disabilities, and as a member of the Patient-Centered Outcomes Research Institute's Patient Engagement Advisory Panel and National Committee for Quality Assurance's Health Equity Working Group.

#### WORKSHOP SPEAKERS

**L. Miché Aaron** is an earth and planetary science Ph.D. student at Johns Hopkins University researching sulfates within Martian craters using remote spectroscopy. She received her B.A. in earth and environmental science from Wesleyan University and M.S. in geographic information systems from Sam Houston State University. She has contributed her efforts to many initiatives, including the Women+ of Color Project, Space Interns, Black in Geoscience, and local astrobiology outreach programs. She also

strives to change the face of STEM by addressing ableism in academia and improving disability representation in underrepresented minority students.

Mariah Lynn Arral is a fifth-year Ph.D. candidate in the Department of Chemical Engineering at Carnegie Mellon University. Her Ph.D. advisor is Dr. Kathryn Whitehead, and her thesis is on mRNA lipid nanoparticle delivery. Before joining Dr. Whitehead's lab, Arral was one of the first researchers in Dr. Halpern's lab at the University of New Hampshire. During her undergraduate studies with Dr. Halpern, she developed an interest in studying neurodiversity and mentorship, for which she has two papers. Additionally, she has been invited to give a presentation on the accessibility and inclusion of disabled students. She has received national and international awards for her research and academic work, including the NIH National Research Service Award Fellowship. She is an openly autistic and dyslexic researcher.

**Edmund Asiedu** is a proud person with disability and a passionate accessibility, disability inclusion, and inclusive mentoring advocate who raises awareness on the needs of persons with disabilities in educational institutions and workplaces. He co-chairs the National Disability Mentoring Coalition and works as the accessibility policy analyst/Americans with Disabilities Act coordinator and serves on the Diversity, Equity, and Inclusion Committee at the New York City Department of Transportation. He has also held positions at Columbia University School of Public Health, National Disability Rights Network, and Ghana Society of the Physically Disabled.

Christopher Atchison is an IPA Program Director in the Division of Equity for Excellence in STEM in the Directorate for STEM Education at the U.S. National Science Foundation where he leads the Workplace Equity for Persons with Disabilities in STEM and STEM Education initiative. He is also Professor of Geoscience Education in the School of Education and Department of Geology at the University of Cincinnati. Through his teaching and research, Atchison advocates for the intentional development of inclusive communities of learning in classroom, laboratory, and field environments. With the use of universally designed instructional strategies, students with disabilities can remain actively engaged and participate in all STEM disciplines. Atchison earned a Ph.D. in Science Education from The Ohio State University and a master's degree in Geology from Wright State University.

Erica Avery recently received her doctoral degree from Johns Hopkins School of Medicine from the Cellular and Molecular Physiology Program where her thesis research was focused on mitochondrial phospholipid metabolism. She was diagnosed with a chronic illness known as fibromyalgia syndrome in 2012 and recently with long COVID in 2022 and began her disability advocacy journey at Johns Hopkins as co-chair of the Equal Access in Science and Medicine Committee from 2019 to 2023, hosting programming and working with leadership with the goal of improving accessibility, awareness, community, representation, equity, and inclusivity. She received her B.S. from Rowan University with a major in biochemistry and minor in journalism. She has written for publications such as *ASBMB Today* and *Scientific American*, and for the American Chemical Society, discussing her disability and health journey.

Cathie Axe is the executive director of Johns Hopkins' Student Disability Services. With more than 30 years of higher education experience, and 27 of those years managing disability services at a variety of institutions, she has had the opportunity to actively engage in the evolution of services as well as perspectives around disability. She received her master's in education with a focus on counseling and development at George Mason University, where she also got her start in disability services. She earned her bachelor's in economics at Brown University, where she served as associate dean and director of student and employee accessibility services, providing accommodations and inclusive services for both employees and students.

Amy Bower is a tenured senior scientist at the Woods Hole Oceanographic Institution in Massachusetts. She studies physical oceanography, specifically the pathways of deep ocean currents in the Atlantic and Indian Oceans from the tracks of acoustically tracked drifting buoys released far below the sea surface. Over the course of her career, she has experienced decreasing vision due to degenerative retinal disease. Assistive techniques such as video magnifiers, computer software that magnifies and reads computer screen content aloud, and access assistants provided by her employer have allowed her to thrive in a STEM career.

**Susanne M. Bruyère** is professor of disability studies and academic director of the K. Lisa Yang and Hock E. Tan Institute on Employment and Disability, Cornell University School of Industrial and Labor Relations in Ithaca, New York. Bruyère serves as institute administrative/strategic

lead, and as the principal investigator/co-principal investigator of research, dissemination, and technical assistance efforts focused on employment disability policy and effective disability workplace practices. She is the principal investigator/project director of the National Policy, Research, and Technical Assistance Center on Employment of People with Disabilities funded by the U.S. Department of Labor (DOL) Office of Disability Employment Policy. She is the author/co-author of five books and more than 180 peer-reviewed articles and book chapters on workplace disability inclusion.

Sheri Byrne-Haber is a prominent global subject-matter expert in the fields of disability and accessibility. She is best known for launching digital accessibility programs at McDonald's, Albertsons, and VMware. With degrees in computer science, law, and business combined with identifying as a disabled person, she has a complete 360-degree view of all the issues affecting disability inclusion and accessibility. Byrne-Haber was named a 2022 LinkedIn Top Voice for Social Impact. Her award-winning blog, which has reached more than 300,000 readers, summarizes legal cases and issues facing people implementing accessibility programs. She is a frequent panelist and speaker at accessibility; user interface/user experience, or UI/UX; and human resources conferences and is an active member of several accessibility committees and nonprofits, helping drive and communicate the evolution of accessibility standards. Her book, entitled *Giving a Damn about Accessibility*, is available for free.

**Ana Caicedo** grew up in Bogotá, Colombia, fascinated by the topics of evolution and genetics. She came to the United States for graduate school, obtaining her Ph.D. at Washington University in St. Louis, and after a postdoctoral experience at North Carolina State University, she joined the Biology Department at the University of Massachusetts Amherst as faculty. Caicedo's research focuses on the genetic basis of plant adaptation, with a particular interest in the processes of domestication and weedy plant evolution. In 2018, with Dr. Michele Cooke, she co-founded *The Mind Hears*, a blog by and for Deaf and Hard of Hearing academics.

**Alison Cernich** is the deputy director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and works to support the institute's mission to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. Prior

to this position, she was the director of the National Center for Medical Rehabilitation Research at NICHD, deputy director of the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury at the U.S. Department of Defense (DOD), and multiple roles at the U.S. Department of Veterans Affairs (VA). She is a board-certified neuropsychologist and is the lead or contributing author on multiple peer-reviewed articles and conference presentations, with an emphasis on disability and pregnancy, traumatic brain injury, and computerized neuropsychological assessment.

**Vivian Cheung** is an RNA biologist and child neurologist. She is the Frederick G. L. Huetwell Professor of Pediatrics at the University of Michigan. Her research focuses on gene regulation and neurogenetic disorders. Her work has shown the import of RNA sequence and structure in the regulation of cell function. Cheung is a recipient of the Curt Stern Award from the American Society of Human Genetics. She is a member of the National Academy of Medicine, and she served as the president of the American Society for Clinical Investigation in 2016. She is one of the founders of the Physician-Scientist Support Foundation, and a determined advocate for a diverse biomedical workforce.

**Jacquelyn Chini** is an associate professor in physics at the University of Central Florida. She completed her B.A. in physics at Drew University in Madison, New Jersey, and her Ph.D. at Kansas State University in Manhattan, Kansas. Chini's research, which is funded by the U.S. National Science Foundation (NSF) and an Innovation Fund grant from the American Physical Society (APS), explores how practices and attitudes in the physics community work to broaden or narrow participation. She is chair-elect of the APS Topical Group on Physics Education Research and an editorial board member for *Physical Review Physics Education Research*.

Rory Cooper is the founder, director, and CEO of the Human Engineering Research Laboratories, a joint venture of the University of Pittsburgh, the VA, and the University of Pittsburgh Medical Center. He also serves as assistant vice chancellor for research for STEM and health sciences collaboration and FISA/PVA Distinguished Professor in the Department of Rehabilitation Science and Technology at the University of Pittsburgh. He is also professor in the Bioengineering, Physical Medicine and Rehabilitation, and Orthopaedic Surgery Departments at the University of Pittsburgh, and holds adjunct professorships at the Robotics Institute of

Carnegie Mellon University and the Department of Physical Medicine and Rehabilitation of the Uniformed Services University of the Health Sciences. Cooper was awarded an honorary professorship at Hong Kong Polytechnic University and an honorary doctorate at Xi'an Jiatong University in Xi'an, China. He has dedicated his career to improving mobility, function, and quality of life for people with disabilities through advanced engineering in clinical research and medical rehabilitation.

Meenakshi Das is a software engineer at Microsoft working on building accessible front-end experiences. She is the founder of the Working with Disabilities support group for working professionals with disabilities, which has more than 4,000 members. For her tech inclusion work, she was inducted into the Susan M. Daniels Disability Mentoring Hall of Fame, named a DO-IT Trailblazer by the University of Washington for changing the way the world views people with disabilities, and she was recently awarded Disability:IN NextGen Leader of the Year. She serves on the Board of Directors of Teach Access, an organization addressing the digital accessibility skills gap among students.

**Ernest (Ernie) Dianastasis** is the founder and CEO of The Precisionists, Inc., a global administrative services and information technology company focused on employing 10,000 neurodiverse professionals over the next several years. In this role, he is responsible for overseeing all aspects of the company, which is headquartered in Wilmington, Delaware, but is national in its focus. Creating meaningful careers for people with disabilities while delivering world-class service to customers is a passion for him.

Wanda Díaz-Merced is an astronomer and the leading proponent of "sonification," a way to turn huge datasets into audible sound. She realized that she could use her ears to detect patterns in stellar radio data and could uncover connections obscured by graphs and visual representation. Díaz-Merced has held positions at the Harvard Smithsonian Center for Astrophysics and the South African Astronomical Observatory. She also co-chaired the 2019 conference Astronomy for Equity, Diversity and Inclusion at the National Astronomical Observatory of Japan. She was awarded the first Google scholarship for people with disabilities and is an honorary ambassador of Soka University in Japan. Díaz-Merced is an important voice and leader in increasing equality of access to astronomy and STEM.

Rasheera Dopson is a public speaker, podcaster, author, and qualitative researcher at the National Center of Primary Care at Morehouse School of Medicine. Her intersectional research approach has supported systems, organizations, and teams to advance equity and mitigate health disparities in multiply marginalized communities through community engagement, policy development, education, and advocacy. She is the founder of the Dopson Foundation, whose organizational aim is the advancement of professional, health, and social equity for women and girls with disabilities.

**Bradley Duerstock** is associate professor of engineering practice and the principal investigator of the Institute for Accessible Science Lab at Purdue University. His research focuses on overcoming functional impairments and health challenges faced by those with disabilities. Duerstock is a recipient of the NIH Director's Pathfinder Award to promote the inclusion of persons with disabilities in the STEM workforce. He has participated in several committees and projects related to accessible biomedical laboratory spaces and is an American Institute for Medical and Biological Engineering fellow.

**Stephanie Feola** is a graduating doctoral student at the University of South Florida and a postdoctoral research associate at the University of Arkansas at Little Rock. They are a discipline-based education researcher in chemistry and biochemistry. Their research interests are centered on understanding and supporting institutional change initiatives focused on integrating asset and evidence-based teaching practices in STEMM higher education.

Anjali Forber-Pratt is a disability activist, a two-time Paralympian, fellow of the American Psychological Association, and the director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the Administration for Community Living. Forber-Pratt serves as the chair of the Interagency Committee on Disability Research, which exists to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs. As a researcher, her primary area of work relates to disability identity development. As a wheelchair user for more than 35 years, Forber-Pratt is nationally and internationally recognized as a disability leader and mentor. She was a White House Champion of Change in 2013, and the American Psychological Association awarded her the 2020 Citizen Psychologist Award for Advancing Disability as a Human Rights and Social Justice Issue Award.

Anupa Iyer Geevarghese is the chief of staff for the Office of Disability Employment Policy (ODEP). She collaborates closely with ODEP's assistant secretary and other DOL leaders to identify and implement strategies for increasing the number and quality of employment opportunities for people with disabilities. Geevarghese draws on years of legal experience in both the public and the nonprofit sectors. She came to DOL from the DOD, where she served as a subject-matter expert and senior disability policy advisor for diversity, equity, inclusion, and accessibility initiatives. Prior to that, she worked for 7 years at the Equal Employment Opportunity Commission (EEOC) Office of Federal Operations, where she was instrumental in implementing updates strengthening Section 501 of the Rehabilitation Act of 1973.

Emily Harris is the executive director of the Disability and Philanthropy Forum. Prior to this, she was the founding executive director of Disability Lead, the nation's first disability civic leadership program, and a senior director at the Chicago Community Trust. In previous positions she focused on regional economic growth, open space conservation, early childhood education policy, nonprofit strategy, and urban planning. Harris earned a B.A. from Oberlin College and an M.A. from the University of Chicago. She is president of Jewish Reconstructionist Congregation and serves on Forest Preserves of Cook County Conservation and Policy Council, and the Local Initiatives Support Corporation Chicago Advisory Board.

Jasmine Harris is a professor of law at the University of Pennsylvania Carey Law School with a secondary appointment at the Penn Graduate School of Education. She is a leading law and inequality scholar with expertise in disability law, antidiscrimination law, and evidence. She writes frequently about disability law for popular audiences with bylines and commentary in such publications and media outlets as *The New York Times*, *San Francisco Chronicle*, *Ms. Magazine*, *The Washington Post*, *TIME Magazine*, *Bloomberg*, and National Public Radio. Harris graduated with honors from Dartmouth College and received her J.D. from Yale Law School.

**Andrew Houtenville** identifies with his deeply rooted personal and family connection to disability. He experiences depression, anxiety, and learning disabilities, mitigated with medication and ongoing therapy, and as a child, he was placed in remedial education due to untreated learning disabilities. Houtenville is an economics professor at the University of New Hampshire,

focusing on applied microeconomics, and is the principal investigator of the Rehabilitation Research Center on Disability Statistics and Demographics, funded by the NIDILRR.

Sam Catherine Johnston is the chief postsecondary and workforce development officer at CAST. In this role, she collaborates with a talented team to increase access to middle- and high-income careers for populations underrepresented in the workforce. She focuses on design-based research, translating universally designed tools and strategies developed through co-design with stakeholders into practical applications in the field to improve education, training, and workplace practices. She is the principal investigator for two NSF grants: one to co-design a multigenerational STEM makerspace in affordable housing, and the other to design a dual enrollment pathway to careers in biomanufacturing, an emerging area within advanced manufacturing. Johnston is also a parent to three spirited children, including her 9-year-old daughter who has Down syndrome.

Jae Kennedy is a professor of community and behavioral health in the Elson S. Floyd College of Medicine at Washington State University in Spokane, Washington. He received a Ph.D. in health services and policy analysis from the University of California (UC), Berkeley, in 1996 and has been teaching and advising graduate students in public health and health administration for the past 25 years. He is a Switzer distinguished research fellow and recent recipient of the Allen Meyers Award for Research, Teaching and Advocacy. He has written more than 60 peer-reviewed journal articles and has been the principal investigator on more than \$3 million extramurally funded grants projects on disability and health policy. He currently directs an NIDILRR-funded postdoctoral training program on disability and health policy, which actively recruits and supports research scholars with disabilities.

**Aaron Konopasky** is a senior attorney-advisor in the Office of Legal Counsel at the EEOC headquarters in Washington, D.C., where he assists the commission in interpreting and applying the Americans with Disabilities Act (ADA) and other federal employment discrimination statutes. Konopasky has participated in the development of regulations under the ADA of 1990, the Age Discrimination in Employment Act of 1967 (ADEA), and the Rehabilitation Act of 1973, as well as numerous policy documents and other EEOC publications. Prior to joining the EEOC, Konopasky earned his J.D. at Stanford Law School, and his Ph.D. at Princeton University.

Raja S. Kushalnagar is a professor and director of the Information Technology undergraduate program and Accessible Human-Centered Computing graduate program at Gallaudet University in Washington, D.C. He earned a Ph.D. in computer science and LL.M in intellectual property and information law from the University of Houston in 2010 and J.D. from Texas Southern University in 2008. As a Deaf professor, he brings consumers, industry, and policymakers together on accessibility issues with a focus on a Deaf/Hard of Hearing perspective and evidence-based research. He has mentored more than 130 undergraduates, including more than 80 who are Deaf or Hard of Hearing. Kushalnagar focuses on increasing the numbers of people with disabilities in the computing pipeline through community involvement.

Angela Lean has more than 20 years of experience working for financial services and technology brands. Her functional expertise spans marketing sales readiness to program management. In her current role as the senior business program lead for accessible employee experience at Microsoft, she manages cross-functional teams dedicated to building an accessible and disability-inclusive workplace environment where employees with disabilities can succeed and thrive. She is also the benefits policy lead for the leadership board of Microsoft's Employee Resources Group dedicated to families and is a member of Yale University's Disability Alumni Group. She was recognized by *Women's Wear Daily* in March 2023 as one of the top 25 most inspirational women leaders of 2023. Lean graduated from Yale in 1993 with a degree in history and earned an M.B.A. from the Stern School of Business at New York University in 1999.

Mark H. Leddy is a program director in the Division of Equity for Excellence in STEM, in the Directorate for STEM Education, at the U.S. National Science Foundation (NSF). Leddy works with the new Workplace Equity for Persons with Disabilities in STEM and STEM Education activity, and on the Alliances for Graduate Education and the Professoriate program. Before joining NSF in 2006, Leddy worked at the University of Wisconsin–Madison, the University of Alaska–Fairbanks, and the University of Wisconsin–Whitewater. He has a Ph.D. from the University of Wisconsin–Madison and an M.S. from Columbia University.

**Megan Lynch** is a nontraditional disabled student who earned a B.A. in art from UCLA and a California teacher's certification to teach social

studies at the secondary level. On behalf of UC Access Now, she wrote the *Demandifesto*, a document that has since influenced other disabled people's movements in higher education. She also created and ran the presentation/panel/workshop "Beyond Law – Providing Accessibility and Inclusion Just Because" for the American Society of Plant Biologists' Plant Biology 2021.

Cassandra McCall is a visually impaired assistant professor in the Engineering Education Department at Utah State University (USU). In her work, McCall leverages emergent qualitative approaches and Universal Design for Research practices in exploring the intersections of disability, identity formation, and cultural implications within engineering and academia. At USU, she is the co-director of the Institute for Interdisciplinary Transition Services. Her work with civil engineering students with disabilities and positionality practices have won best paper awards both nationally and internationally. She is an advocate for the increased participation of people with disabilities in the engineering fields and is a founding member of the Equity, Culture, and Social Justice in Education Division of the American Society for Engineering Education.

Melissa McDaniels is the associate executive director and associate scientist at the Center for the Improvement of Mentored Experiences in Research at the University of Wisconsin–Madison. She is a co-investigator and community advancement manager for the NIH-supported National Research Mentoring Network. In her prior role as a member of the Michigan State University (MSU) Graduate School leadership team, McDaniels worked to support graduate students and postdocs as they developed their capacities as postsecondary instructors and mentors. Previously, she served as director of their NSF ADVANCE Grant where she spearheaded efforts to diversify their STEM faculty. In this role, she was responsible for the development and implementation of MSU's new faculty mentoring policy. McDaniels has more than 20 years of experience in graduate student and faculty development, undergraduate and graduate teaching, and learning and organizational change.

**Marcia McNutt** is a geophysicist and president of the National Academy of Sciences. She previously served as editor-in-chief of the *Science* journals, and the director of the U.S. Geological Survey, where she was awarded the U.S. Coast Guard's Meritorious Service Medal. McNutt also served as pres-

ident and chief executive officer of the Monterey Bay Aquarium Research Institute and as the president of the American Geophysical Union (AGU). She holds membership in numerous professional organizations, in addition to being the recipient of several honorary doctoral degrees. She is a fellow of AGU, the Geological Society of America, the American Association for the Advancement of Science, and the International Association of Geodesy.

Edward Ombati Manyibe is the capacity-building director and research associate professor at the Rehabilitation Research and Training Center on Research and Capacity Building for Minority Entities at Langston University (LU-RRTC). He has served as co-principal investigator on several NIDILRR-sponsored projects at the RRTC, focused on both enhancing minority-serving institution research capacity and improving disability and rehabilitation services for multiply marginalized people with disabilities. He has authored or co-authored numerous peer-reviewed research publications, monographs, and policy briefs on topics such as mentorship and research-capacity building. He is the recipient of the National Association of Multicultural Rehabilitation Concerns Bobbie Atkins Research Award.

Karen Marrongelle is the chief operating officer of the U.S. National Science Foundation (NSF), where she oversees operations of the \$10 billion federal agency whose mission includes support for all fields of fundamental science and engineering. Previously, she served as assistant director of the National Science Foundation's Directorate for Education and Human Resources. Prior to joining NSF, Marrongelle was dean of the College of Liberal Arts and Sciences at Portland State University and professor of mathematics and statistics, where she oversaw 24 departments and programs across the humanities, social sciences, and natural sciences. Marrongelle has a Ph.D. in mathematics education from the University of New Hampshire and a master's degree in mathematics from Lehigh University.

Lisa Meeks is an associate professor of learning health sciences and family medicine at the University of Michigan Medical School. She is also the executive director of the DocsWithDisabilities Initiative, co-creator of their social media campaign, and co-host of their podcast. She is widely considered the leading expert on disability inclusion in health professions education and is the editor of two ground-breaking books on the topic of disability inclusion in health sciences. Her work has been published in

leading medical journals and has also been featured in several media outlets. Meeks also regularly collaborates with health professions associations and is the lead author of the Association of American Medical Colleges special report Accessibility, Inclusion, and Action in Medical Education: Lived Experiences of Learners and Physicians with Disabilities.

Kate Mittendorf is an interdisciplinary translational genomic scientist focused on translational genomics and digital health interventions, with particular focus on ensuring that precision medical and digital health approaches close, rather than widen, existing health gaps for medically marginalized populations. They has been a key contributor to a number of large genetics consortia and associated clinical trials, including the National Human Genome Research Institute (NHGRI)–funded Clinical Sequencing Exploratory Research and ClinGen consortiums as well as the NHGRI-funded eMERGE Network. They have a passion for improving scientific communication with accessible visual aids and associated image description alt-text; their illustrations have appeared on journal covers, in textbooks, in biotechnology curricula, and on scientific knowledge resource websites. They have also designed and developed resources for improving access for disabled scientists and research participants, which are made freely available on their website.

Michelle Olson graduated with a bachelor's degree in human-centered computing from the Rochester Institute of Technology (RIT) in May 2023, and is presently enrolled in the Human-Computer Interaction master's program at RIT. She works in the Center for Accessibility and Inclusion Research (CAIR) Lab as a research assistant with Dr. Kristen Shinohara and Ms. Loam Shin on a project that explores various methods for guaranteeing accessibility to users and designers who are Hard of Hearing or Deaf using the think-aloud protocol approach. Prior to her position as a research assistant, Olson served as an American Sign Language consultant for the RIT Department of Access Services.

**Kimberly J. Osmani** is a senior extension associate with Cornell University's Yang-Tan Institute on Employment and Disability. In her position, Osmani is the project director for the Center for Advancing Policy on Employment for Youth, or CAPE-Youth. She is also part of a team leading an initiative with the Oregon Vocational Rehabilitation Agency, Inclusive Career Advancement Program, helping people with disabilities access post-

secondary education within community colleges working through career pathways. Osmani has extensive experience in working with youth with disabilities—first as a special education teacher, then as an associate state director of special education services at the Oklahoma State Department of Education, and finally, as the statewide transition coordinator for the Oklahoma Department of Rehabilitation Services.

Alyssa Paparella is a third-year Ph.D. candidate at Baylor College of Medicine and a 2023 HHMI Gilliam Fellow. She is a passionate disability advocate. In 2020, Paparella created the DisabledInSTEM platform, where she sparks conversations regarding disability inclusion and access within STEM. Additionally, she founded a DisabledInSTEM Mentorship Program, which is currently in its third year, as she believes mentorship is vital to success within STEM. Through her platform, Paparella has had an effect at multiple institutions, conferences, and national organizations to raise awareness of disabled scientists.

**Yvette E. Pearson** is vice president of diversity, equity, and inclusion at the University of Texas at Dallas. She is a fellow of the American Society of Civil Engineers (ASCE) and the American Society for Engineering Education. Pearson is recognized globally for more than 25 years in higher education, particularly for her work to advance sustainability, justice, equity, diversity, and inclusion. Her efforts have led to changes in policies and practices of universities and global engineering organizations, including, but not limited to, increased equity and inclusion for individuals with disabilities. Among Pearson's awards and honors are ABET's Claire L. Felbinger Award for Diversity and Inclusion and ASCE's President's Medal. Her podcast, *Engineering Change*, has audiences in more than 80 countries. Her book *Making a Difference: How Being Your Best Self Can Influence, Inspire, and Impel Change* was released in February 2023.

**Luis Pérez** is the disability and digital inclusion lead for CAST, and his work is embedded with the Postsecondary and Workforce Development group. In this role, he promotes the creation, delivery, and use of high-quality accessible educational materials and technologies to support equitable learning opportunities for all students. He works to increase access to middle- and high-income careers for populations underrepresented in the workforce, including people with disabilities. His perspective is informed by his own lived experience as a person with a disability and multilingual learner. Pérez

has published three books on accessibility, mobile learning, and Universal Design for Learning (UDL): *Mobile Learning for All, Dive into UDL*, and *Learning on the Go.* He currently serves as a transition and workplace accessibility strand advisor for the Assistive Technology Industry Association.

Joey Ramp-Adams is the founder and CEO of Empower Ability Consulting Inc., a firm that advocates for people with disabilities in STEM, focusing on service dog handler access to equal opportunities in science. With a background in biocognitive neuroscience and as a neuroscience research affiliate at the Beckman Institute for Advanced Science and Technology, Ramp-Adams saw a gap in disability access to science education and career opportunities. She is also the co-founder and vice president of the International Alliance for Ability in Science. This nonprofit organization provides resources, financial aid, and scholarships for student scientists with disabilities.

Matthew Seita is a recent doctoral graduate from the computing and information sciences Ph.D. program at the Rochester Institute of Technology. He is an accessibility and human—computer interaction researcher, and while earning his Ph.D., he conducted research at the CAIR Lab at RIT, advised by Dr. Matt Huenerfauth. His work was generously supported by the U.S. National Science Foundation (NSF) Graduate Research Fellowship and the RIT AWARE-AI NRT Fellowship. Currently, Seita works for Dr. Raja Kushalnagar as a research assistant at Gallaudet University and continues to work on research involving improving accessible technologies for the Deaf and Hard of Hearing. Seita is profoundly Deaf and fluent in English and American Sign Language.

**Loam Shin** is a fourth-year undergraduate human-centered computing major at the Rochester Institute of Technology. She works as a research assistant in RIT's CAIR Lab under the mentorship of Dr. Kristen Shinohara. Along with her colleague, Michelle Olson, they are conducting a project to investigate different ways to make the think-aloud protocol accessible to Deaf/Hard of Hearing designers and users.

**Kristen Shinohara** is an assistant professor in the School of Information at the Rochester Institute of Technology where she co-directs the CAIR Lab. Her research is at the intersection of human–computer interaction, accessibility, and design, with a focus on accessible design, research, and

computing education. Her NSF-funded research projects focus on how to empower disabled graduate students and designers, and on how to improve accessibility practice in the tech industry and in computing education. She is a recipient of a 2022 Google Scholar Award to improve the think-aloud design method for Deaf and Hard of Hearing users and designers.

Barbara R. Snyder is president of the Association of American Universities. Prior to that, she served as president of Case Western Reserve University from 2007 to 2020. She was a faculty member at the Ohio State University (OSU) from 1988 to 2007, and she served as executive vice president and provost from 2003 to 2007 and held the Joanne W. Murphy/Classes of 1965 and 1973 Professorship at OSU's Moritz College of Law. She is an elected member of the American Law Institute. She currently serves on the Board of Directors of the National Humanities Alliance and was previously the chair of the Board of Directors of the American Council on Education and the Business-Higher Education Forum and vice chair of the Board of Trustees of Internet2.

Caroline Solomon is a marine ecologist who focuses on nutrient cycling and phytoplankton physiology. She is heavily involved in research that looks at water quality issues in local waters, such as the Anacostia River that flows through Washington, D.C. Solomon's work also includes mentoring Deaf and Hard of Hearing students in the classroom, through providing internship opportunities, advising students as they navigate graduate school, and she is one of the organizers of the 2023 Global Year of STEM Sign Language Lexicons looking at the ethical and linguistic underpinnings, effectiveness for K–12 education, and their sustainability for future generations.

Hari Srinivasan was diagnosed with autism and ADHD as a toddler. While his spontaneous talking skills are a work in progress, he primarily uses augmentative and alternative communication to communicate. His autism presents numerous other challenges that present significant obstacles to his daily living. Srinivasan graduated from the UC Berkeley, and is a Ph.D. neuroscience student at Vanderbilt University, a PD Soros fellow, a Public Voices fellow, and a Neurodiversity Inspired Science and Engineering fellow at the Frist Center for Autism and Innovation at Vanderbilt. His non-academic affiliations include the U.S. Department of Health and Human Service's Interagency Autism Coordinating Committee, Disability Rights

Education and Defense Fund, Autistic Self Advocacy Network, Autism Society of America, International Society for Autism Research, Brain Foundation, and Duke University's Analytics Center of Excellence.

Mahadeo Sukhai is the world's first congenitally blind geneticist. He is vice president of research and international affairs and chief accessibility officer for the Canadian National Institute for the Blind, having previously served as a researcher at the University Health Network in Toronto. Sukhai is a leading expert on accessibility of graduate and postdoctoral research training in science, technology, engineering, mathematics, and healthcare disciplines. He is the chair of the Employment Technical Committee for Accessibility Standards Canada, as well as the external co-chair of the Canadian Institutes of Health Research Expert Advisory Committee on Accessibility and Systemic Ableism.

Laureen Summers manages the American Association for the Advancement of Science Entry Point! Program, which recruits, screens, and refers undergraduate and graduate students with disabilities for summer internships to partners in industry and university research programs. A woman with cerebral palsy, Summers advocates for students and scientists with disabilities to be included and recognized for their talents and contributions to every STEMM venue. She is fierce about the importance of building relationships as a way of contradicting the assumptions and stereotypes about the potential of people like herself. She published her first chapbook of poetry, *Contender of Chaos*, in 2020 and is completing a second manuscript, *Dancing to the Moon*.

**Dean J. Tantillo** is a professor of chemistry at UC Davis. His research can be broadly described as applied theoretical organic chemistry and spans the disciplines of organic, physical, computational, mechanistic, medicinal, natural product, and organometallic chemistry. He also has a long-standing interest in making chemistry accessible to the Blind and Visually Impaired. Tantillo has won multiple awards for his teaching and mentoring, including UC Davis' campuswide awards for both undergraduate and graduate teaching (the only faculty member to win both), the Inclusion and Diversity Prize from the Royal Society of Chemistry, and an ADVANCE Scholar Award from UC Davis, which acknowledges "faculty who advance diverse perspectives and gender equity in STEM through their teaching, research and service."

**Holden Thorp** is the editor-in-chief of the *Science* family of journals. Prior to joining *Science*, he spent 6 years as the provost at Washington University in St. Louis and was the chancellor of the University of North Carolina at Chapel Hill before that.

**John Tschida** is the executive director of the Association of University Centers on Disabilities. He has spent more than 20 years using data and research to drive policy change and service development for individuals with disabilities. Tschida, who has lived with a spinal cord injury since 1993, serves on several public and private boards designing policy or governance solutions to further the independence of people with disabilities.

Hoby Wedler has been completely Blind since birth. He is a chemist, an entrepreneur, and a sensory expert, and is driven by his passion for innovative, creative, and insightful thinking. He earned his Ph.D. in organic chemistry from UC Davis in 2016. Prior to that, he founded a nonprofit organization to lead annual chemistry camps for Blind and Visually Impaired students throughout North America. In the same year, he began opening doors to the world of wine aromas by developing Tasting in the Dark, a truly blindfolded wine experience, in collaboration with Francis Ford Coppola. He has since expanded the program to a global market in a variety of industries and special projects. Wedler uses his highly trained palate and acute sensory insight of his surroundings in his work as a sensory expert and product development consultant. He now works as a global motivational speaker, scientist, mentor, educator, and entrepreneur. President Barack Obama recognized him by naming him a Champion of Change for enhancing employment and education opportunities for people with disabilities. Wedler believes that everyone should pursue their dreams, challenge themselves, and elevate their happiness as they grow and progress through life and their careers. He is committed to making the world more inclusive and accessible for all.

**Taryn M. Williams** is the assistant secretary of labor for disability employment policy at the U.S. Department of Labor. In this position, she advises the secretary of labor on how the department's policies and programs affect the employment of people with disabilities and leads the ODEP, which works with employers and all levels of government to promote evidence-based policy that improves employment opportunities and outcomes for people with disabilities. Previously, she was the

managing director for the Poverty to Prosperity Program at American Progress. There, she worked on a variety of issues related to education and workforce policy.