

National Academies of Sciences, Engineering, and Medicine

Leading Practices for Improving Accessibility and Inclusion in Field, Laboratory, and Computational Science – A Conversation Series

Transcript of live webcast of Conversation #2.

NOTE: This is an unedited transcript of a live webcast event that was prepared for the Accessibility and Inclusion in STEM conversation Series held on January 25, 2022. The transcript was prepared by Julie Snyder (of Purple, LLC) and reviewed by Katalyn Voss (NASEM), and is not an official report of National Academies of Sciences, Engineering and Medicine. Opinions and statements included in the transcript are solely those of the individual speakers at the Accessibility and Inclusion in STEM conversation, and are not necessarily adopted or endorsed or verified as accurate by the National Academies.

>> Rory: Welcome, everyone, to the second event in the national academies of sciences, engineering and medicine conversation series on accessibility and inclusion in STEM.

I'm Dr. Rory Cooper, and I'm chair of the -- of our planning committee. And I appreciate you joining us today. This conversation in this -- is the second in a series of five conversations.

We hope that you were able to watch the prerecorded keynote lectures by our speak, before attending today's live meeting. However, they are posted online and you can view them after the event.

We're very happy for the two excellent presentations that were provided, and I'm sure that you will enjoy learning from them.

Our goal is that this event will offer the opportunity for active discussion among the speakers, panelists and those of you when are listening via Slido.

For those who you viewing Slido you can ask Q&A questions in the website and we will consolidate your questions and bring them into the discussion.

Before we get started with our program, I'd like to introduce each of the members of our planning committee. So I'd first like the call on Dr. Emily Ackerman to introduce herself.

>> Emily: Hello. My name is Emily Ackerman. I'm a post doctoral researcher at Harvard Medical School. I use she/her pronouns, and thank you for coming today.

>> Rory: Thank you, Emily. And next I'd like to introduce Dr. Cheryl Berkistahler. Cheryl? All right.

Then we'll move on to Dr. Julian Brinkley.

>> Julian. Hello, everyone. Dr. Julian Brinkley, assistant professor of human centered computing at Clemson University and the director of the drive lab. I use he/him pronouns and I'm an early 40s black male with a beard. Thank you.

>> Rory: Thank you, Julian.

Dr. Chris Atchison?

>> Chris: Good morning, folks. Chris Atchison, professor of geoscience education at the university of Cincinnati. White male, no hair, beard, glasses, and a big smile. Good to see you all.

>> Rory: Dr. Caroline Solomon?

>> Caroline: Yes, hello. I'm a province for the biology department. I'm also the director of school of science, technology and accessibility in mathematics in public health. We like to say that we make a stamp on our student's futures here. I use pronouns she/her/hers and my background is a wall with a globe sitting to my right.

And I am wearing a red shirt. I identify as a woman. And thank you all so much for joining our conversation today.

>> Rory: Great, thank you, Caroline. I should say I'm Rory Cooper. I'm a white male, early 60s, a veteran of the United States army, wheelchair user and I use the he/him pronouns. And I -- and my

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background is a -- is a bookshelf with various knick-knacks on it.

Well, thank you. So at this point, I'm going to turn over the moderating to Caroline Solomon, who will be our moderator for today's discussion on accessibility, inclusion in STEM in the context of laboratory-based research and education. Thank you, Caroline.

>> Caroline: Yeah, before we get into our conversation today, and introduce our presenters and keynote speakers, I wanted to give the opportunity to give a brief overview of today's highlights and their presentations.

And I wanted to also invite the public in this opportunity. So we wanted to go ahead and give the opportunity for you guys to go ahead and watch our prerecorded conversations before we get into the discussion today.

But if you weren't able to watch the prerecorded conversations, they are posted online and available for your later viewing. We do have some keynote speakers for this event today. First I'd like to introduce Brad. He practices at the Walden school of biomedical engineering and the school of industrial engineering at Purdue University, so if you'd like to introduce yourself, Brad and get started.

>> Dr. Duerstock: It's a pleasure. Thank you, I'm Brad Duerstock, I'm a professor of practice at Purdue University. I use the pronouns he/his/him. I'm a white male and a tetraplegic wheelchair user due to a spinal cord injury.

In my full presentation, I mentioned some strategies for increasing accessibility and productivity in the biomedical lab environment. I also discussed why being able to actively participate in biomedical labs is imperative for promoting the inclusion of people with disabilities in STEM fields.

Traditional biomedical or wet labs are pervasive in secondary and post-secondary institutions and research centers. These are really the forges in which scientists and engineers in the life sciences are created.

The whole pedagogy of the life sciences in medicine are founded on the principle of activity-based learning and providing students practical or hands-on lab experiences. Too often the focus of ADA compliance in the past has been really providing students with disabilities access to labs.

But not to be active participants. Thus, there's a lot of barriers to people with disabilities from achieving an ultimate career in STEM. We believe that by enabling students with disabilities to be as independent as possible is important to be as successful in undergraduate STEM education and very critical to post-graduate education and conducting research and being skilled in the medical arts.

We acknowledge that there is a need for multiple strategies, though, to help students with disabilities to be successful in the lab sciences, including universal design features in laboratories and developing accessible lab equipment.

There is also a need to improve the training of instructors and TAs who are at the forefront of teaching new students with disabilities to be proficient in lab activities and not to be discouraged from entering STEM.

There needs to be a better definition of what lab assistants are needed for students and what their roles are.

Virtual lab training has its place as well. And critical, I think, also is to provide students as many other training options, opportunities, such as internships.

But beyond that, I think there also needs to be a re-evaluation of what qualifies as being successful in STEM.

To ultimately achieve a career as a scientist or engineer. There are other barriers to inclusion such

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as timelines that are expected in order to graduate or reach tenure, attitudes toward people with disabilities being in STEM. Necessary funding, support mechanisms.

And just other supports such as mentoring and other activities that many able bodied students might benefit from, but are not available to those with disabilities.

So greater inclusion really improves conditions for everything. It's a rising tide that lifts all posts. Better human factors and lab accessibility increases efficiency, decreases repetitive motions, stresses. The input of people with disabilities leads to diversity of thought, insights in the lab, different disciplines in STEM, new perspectives in terms of healthcare, medicine, human computer interaction and other engineering fields.

So I think I'll stop there so we can gauge others in this -- engage others in discussion, but I want to first really thank the nation National Academies of Sciences, Engineering, and Medicine's and this program for giving this opportunity to speak, and thank you very much.

>> Caroline: Yes, thank you, Brad. I'd now like to go ahead and introduce our second keynote speaker, Dr. Theresa Edelman. Dr. Edelman earned her Ph.D. from the university of Minnesota and the molecular, cellular development and biology genetics program. She is currently to co-PI of S STEM, which is scholarships in STEM. She is also involved in the mentorship program and biology instructor at Minneapolis technical and community college.

If you'd like to go ahead, Theresa.

>> Dr. Edelman: Thank you so much for that introduction. My name is Theresa Edelman. I use she/her/hers pronouns and I'm an instructor at Minneapolis community and technical college.

I am a white woman with brown hair, brown eyes, I'm wearing an orange sweater. And in the background is a light blue wall and two white doors.

I was born with a genetic mutation, which results in achondroplasia dwarfism. It's the most common form of dwarfism, and I stand about 4 feet tall. My disability actually kind of sparked my interest in science because I -- it caused me to think at a very early age about the implications of the genetic mutation that I carried.

I've worked in several wet labs throughout my career, starting in high school, college. After college I was a soon you Junior scientist and I went to grad school and now I'm an instructor and have taught in a number of different wet labs. Getting around labs with high benches and tall stools is difficult for people with disabilities to access inaccessible spaces such as labs, often times accommodations need to be made in order to provide access.

Some accommodations I explained in my talk can be in the form of assistive technology, which is any sort of device or technology that helps disabled people perform tasks that would otherwise be difficult or impossible to do.

In most spaces, I use a step stool to access my environment, including counters, lab benches and equipment. And while accommodations can provide access, they don't provide inclusion because they -- because receiving an accommodation, there's a number of barriers in order to achieve that.

And that often times -- or that needs to happen and begin with self-advocacy. I explained in my -- shared in my talk that self-advocacy was very difficult for me because I believe drawing attention to my disability gives people a reason to feel that I was unqualified or incapable of, you know, succeeding.

I also talked about ways that we can make environments more inclusive through universal design. Universal design creates spaces and tools that can be used by everyone, not just the average able-body

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user.

One example that I shared about universal design feature that I benefited from was a height adjustable table in the lab that I did my Ph.D. thesis work. And this universal design feature was very powerful because I no longer needed to use a step stool, and I didn't need an accommodation in order to receive that access.

And so these kinds of, you know -- this universal design philosophy and method of thinking can go a long way in providing other people with disabilities access to lab environments.

Creating accessible spaces isn't the only thing that we need focus our attention on. I talk little bit about making sure that events are accessible, especially events that are essential for progress within the field.

But if our goal is to create an inclusive environment, we also need to address some of the negative biases and ableism that prevents people from disabilities from being respected and valued.

Often people with disabilities are not expected to succeed or not seen as having valuable distributions to make. I shared a story from my personal experience about how one of my chemistry instructors in high school thought that I wouldn't do well in his class because of -- because I was a disabled student. And that kind of thinking is discriminatory and harmful.

And thinking back on that experience, and advice that -- or ways that I would like to change that kind of thinking to be more productive and supportive is instead of, you know, making assumptions about what people can and can't do, ask how can we ensure that person is included, what does this individual need to succeed.

I shared a statistic from -- from a journal article from Dr. Swenor et al, who is on the panel with us, that they reported a disability decline from 1.9% in 2008 to only 1.2% in 2018, and to me that's very concerning and it's imperative we work to create an environment in which the STEM field not only supports but values people with disabilities and the perspectives that -- and creativity and, you know, influence that they're able to contribute to the field.

So I look forward to the discussion today, and I thank the national academies for using this platform to bring awareness to some of the changes that need to be made in the field.

>> Caroline: Thank you so much, Theresa, so I want to take the opportunity to introduce our other panelist, who is joining us today for the structure of the conversation. And so that would be Dr. Edelman and Dr. Deurstock, and that will be lead by Dr. Bonnie Swenor, and Dr. Swenor is a -- is an associate professor and also in the institute at Johns Hopkins and in the school of public health at Johns Hopkins.

I apologize for the interpreting delay.

We also have Dr. Nils Hakensson, who is a professor at the graduate coordinator in the department of biomedical engineering at a state university, so welcome to the conversation.

So now I would like to kick it off with some structured questions for the panelists and the planning committee members that we have with us today. For those who are listening to the web cast video, please add your questions and thoughts through the Q&A chat, and we will incorporate your ideas into this conversation from the Slido website.

The first question is about the diversity and the lab experience environment. With accessibility and inclusion, what is a unique perspective that we can use to have implemented by scientists and lab directors using universal design? What would that look like? And what innovative tools can be created to allow for more accessibility in those environments?

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Who would like to answer this question first?

>> Dr. Duerstock: I'd be happy to take a stab. What we find is, you know, just in terms of being able to get around, reconfigurability of the lab environment. Right now you think of most labs you had in high school, and the fixtures are really -- it makes it very difficult to get around, the height of the lab benches, the narrowness of the spaces in between.

Now with height adjustable lab benches with wheels and, you know, getting electricity from the ceiling versus, you know, based on the floor, we can really open up a space if we need to.

And really accommodate the movements of a lot of people, whether they're blind or have mobility impairments. And also it really not only allows for greater accessibility for that student, it also opens up a communication between the peers.

If I wanted to talk to someone across the room, you know, I would have to navigate around all these stools and lab benches and it's pretty much impossible.

And so just having this kind of an open space concept really helps.

>> Nils: I can add something. I'm Nils Hakannson, I'm at Wichita State University, male, 55 years old, graying black hair, bad hair day and a blurred background so you don't see my cluttered office.

I also have muscular dystrophy, and use a wheelchair for mobility, limited dexterity, so some of the components of my lab are, you know, mostly focused towards wheeled mobility or mobility limitations because that's what I know, but we have in the past worked with schools and we would bring in, like, summer camps essentially, high school students and really focused towards kids disability.

One year we worked with envision, which is a non-profit group here in Wichita, focused for people who are blind or visually impaired. We had a number of lab activities in our different biomedical labs. I run a biomechanics lab, so we use video motion capture, electromyography, which is like electrocardiogram, but for skeletal muscles, we have force plates and we do walking studies, jumping, rolling is a research we're working on.

And one of the challenges fittingly for participants who are blind or visually impaired is looking at signals, and that's largely what we do with electromyography, it's squiggly line on the screen and we also realized we could hear it and we could take those signals and attach it to an amplifier for -- and plug in headsets.

Now, typically we'll look at multiple muscles when we're looking at some kind of a study, so you have to switch between those different muscle, but that was at least one area that we felt that we could be more inclusive and provide somebody some -- a different perspective.

And even for people who are not blind or visually impaired, to hear the muscle activity is also kind of an interesting approach. Being able to tell if a signal deviates in a way that you might not notice if you're just seeing it.

>> Fortune Bonnie: I'm Bonnie Swenor, and I'm an associate professor actually at the school of nursing and the School of Medicine and public health at Johns Hopkins and the founder and director of the disability health research center here at Hopkins.

I use she/her pronouns and I'm a white woman with blond hair in my mid-40s and I want to first say thank you for having this panel to the national academies and thank you to Theresa and Brad for their phenomenal keynote talks, and I just want to reiterate that everyone in the audience should take time to listen and watch them. They're impressive and so important.

And in adding to this conversation, I also want to elevate that the lab spaces are important, but so is the space around them. To get to lab, to get to where you need to be on a campus or at a research

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institution matters as well. And that should be universal design of honestly the entire space critical. Someone needs to go the lunch to use the restroom, to go to a conference meeting.

Theresa talked about this beautifully in her talk. And so I think we really do need to consider both certainly inside the lab and inside spaces where research is being done, but really it's the whole dimension of a campus and research experience.

>> Caroline: Fantastic, yes, thank you for sharing. And I would also like to share what we've been doing at Gaudet University for how deaf people use the land spaces so that we can -- we've been incorporating the concept called deaf space.

And that is thinking about color, lighting, and how deaf people can move around to be able to see each other. And some of the results of our work, examples being the lab benches are not black, like traditional lab benches, they're actually gray, because those are easier on deaf folks' eyes, and we also talk about what lights we use so that it doesn't cause eyestrain because we are constantly watching and using our eyes.

One of the most fun parts about designing our lab spaces was actually setting up a mock lab in a warehouse. And using go pro cams are to track people's motions, and we realized that a traditional lab design is just not conducive for deaf people.

And we wouldn't be able to instruct in a traditional setting with a teacher at the front at their own bench because the deaf students wouldn't be able to see the professor.

It was reallyying to see how we used the lab and the intentionality for other people to be able to use that kind of universal design concept as well.

Anyone else want to add? Theresa?

>> Dr. Edelman: Thank you for sharing your perspective, Caroline, and others. I think kind of a big overarching theme is that one size doesn't fit all. That adaptability and ways to, you know, modify and change the environment to allow for somebody with a disability to come in and create the space to work well for them, you know, open floor plans and modular furniture that can be moved and changed, you know, if there's loud spaces, making sure that there's also quiet environments for people who get distracted or if noise is a concern.

But one of the things that I would like to point out is that a lot of times we focus on kind of how this benefits people with disabilities, but both universal design as well as assistive technology can benefit everyone.

And a lot of these kinds of things have become common place in our environment. A lot of technologies that started out as assistive technologies for disabled people have become household goods.

For example, Siri, being able to use your voice to send a text message or audio books, to be able to listen to a book without having to read the words, as well as text messaging. So when we're thinking about creating these spaces and putting resources into making things accessible, that it benefits everybody, not just disabled people.

>> Caroline: Thank you. Very well said. And are there any other thoughts or considerations that other panelists want to put forth before we move on to the next question?

Okay. So then the next question, here we go. So how do we distinguish between accessibility and inclusion within the lab environment? For example, in your presentation, Nils, we talk about accessibility and the difference between accessibility and inclusion and the intersection between those two things.

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And what conversations need to happen in order for us to have both within a lab environment?

Sure, Theresa.

>> Dr. Edelman: I guess it depends on how you define accessibility and inclusion. The way I like to think about accessibility is when people can, you know, engage in the same activities, acquire the same information and enjoy the same services as a person without a disability.

I think about being able to go into a space, be able to communicate with those around me and function and work in the space similarly to others.

I think of inclusion as going further, not only providing support and access, but also value and respect. Inclusion means that people with disabilities have a seat at the table, we're able to access and participate in the conversation, our voices are heard, and we have input and impact in decisions that are being made.

I think when we ask what kinds of conversations need to happen, we need to ask ourselves what we value. A lot of times work that is being done focus on productivity, how many hours you're in the lab, how many papers you're publishing, how quickly you're getting your Ph.D. completed, rather than valuing kind of the perspective and experience and significance that a person with a disability can contribute.

And asking, you know, does their experience matter. Can they contribute something in a different way if they're not able to do the same things that able-bodied people are able to do. And I think in order to do that, we really have to think outside the box.

And so I'll -- yeah.

>> Bonnie: this is Bonnie. I completely echo what Theresa just said. Inclusion is part accessibility, but part addressing the ableism, the negative stereotypes around disability, and you really have to address both to get to a place of inclusion.

You know, I very much appreciate this conversation because these ideas are not happening enough in STEM or in higher education.

We're not talking about disability enough as part of dimensions of diversity, equity and inclusion, and when we are, it tends to be solely housed around accessibility and leaves off that component of the culture, the climate, the ableism.

And we have to address both to really see change for this community. And I think that's so critical. I also just want to elevate in line with what Brad talked about in his keynote, is we have to change this view that is pervasive in lots of spaces and feels extremely pervasive in higher ed and STEM, the future isn't to focus on changing the person, to fix the person, it's to create the inclusive environment.

And I find often that that message is not being heard or recognized. And I think Brad outlined very eloquently the history behind sort of those viewpoints. So, again, I just reiterate everyone should watch that -- his talk. But I think that's where we should go. We need both components, we need anti-ableism and universal design.

>> Nils: Sorry, I got -- I got snafued here with a bad track path. And I -- I'm a little bit lost here, so I may be repetitive and I apologize for that. When I think about accessibility, I think about the physical environment and it's a facilities and the structure and the inclusion is much more of the social and the understanding and bringing people in and recognizing the and, you know, just even from a perspective of there's something different and being able minded, and whether it's a disability or a different culture or different language, a different message on one's T shirt, to be able to say, you know, come in and let's work together and see what's going on and compromise and learn from each other.

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>> Caroline: Yes, did you want to go ahead and add? Theresa, did you have any additional thoughts or comments there?

>> Dr. Edelman: One thing I wanted to kind of -- I mean, it's kind of -- it's kind of been mentioned in Dr. Deurstock's talk, but I also want to kind of highlight, in the STEM field, science and medicine especially, often times we really focus on the medical model of disability in which disability is a defect that needs to be fixed until we reach what we consider, quote, unquote, normal.

And we have to disconnect what we're doing in research and medicine from what we, you know -- how we value people. And, you know, Dr. Deurstock mentioned the social model, which, you know -- in which a disability is viewed as a social construct in the social barriers.

But also I want to point out that there's also a model that goes even further, the disability pride model, in which disability with a capital D is a culture as well as an identity that we as disabled people hold a lot of pride in.

I think my disability makes me unique and amazing, and as well as, you know, my family and the other people in the disability community. And in order -- like, I hope that we can move towards that mindset in which we're celebrating disability. We're not looking at it as a negative thing, but something that makes people with disabilities amazing and unique and the diversity that they're contributing to society.

>> Caroline: Yeah, that's great. And, Brad, did you have an additional insight there?

>> Dr. Duerstock: And I just -- something that Theresa just said about disability. And I think I might be preaching to the choir. But, you know, as a cultural aspect, disability is so -- I say it's part of the large -- probably the largest minority we have, affects all genders, affects all socioeconomic groups, all races.

And as someone with a mobility impairment, I don't claim to have any great insight on what it's to be deaf or blind, and so it's -- all these perspectives, you know, helps me, even though I'm part of the disability community, it's such a rich area that there's always lessons to be learned.

So it's a -- that's all I wanted to add.

>> Caroline: I want to add to the comments that you guys have made here today. That all of us have our own individual stories. Kind of an example of ableism. All of us within the disabled community, we have the prejudice of ableism. That's something that we all have. In the deaf community, we all that audism.

>> In which we experience oppression by people who can hear.

And just another example of ableism, you know, I can think of times when I have gone in to give presentations or getting letters of recommendations for students who need job opportunities, and they'll always say things like, you know, she's great in the lab or things like that, but you know, nothing was never given real opportunities for experiments and things like that.

And just different examples of ableism and being removed from specific opportunities. What we need to recognize is, as you said, people with disabilities provide this unique, diverse experience and something to learn and something that can be contributed to these environments.

So, yeah, Bonnie?

>> Bonnie: Yeah, this is Bonnie. Thank you for sharing that. You know, I find it striking that, you know, 30 plus years after the ADA and I'll pause to say the ADA is not a fix all for disability inclusion, but has taken us to some great advancements.

I'm still struck by how pervasive those stories are, you know, similar to what you just shared,

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particularly in STEM and higher education. You know, I think the bias and the ableism is actually quite profound and not always intentional, but still profound. Meaning I think it's still so unrecognized that it is not okay, and it's just unknown.

You know, I'll share my own personal story that was a critical turning point, was early in my career I had a colleague approach me about a project. They didn't know about my disability. I have a visual disabilities. I have low vision. We met in person. They handed me a piece of paper and I couldn't see it, and I disclosed my disabilities. And the person said, you know, I don't think this is going to work out.

I don't understand how you can see your data. I don't think I could ever trust your work if you can't see your data. And, you know, the project went on without me, right?

And I think when I told that story, people are shocked, but there's also sometimes a moment of pause that is sort of like, yeah, how do you do your work, right? And it's that pause that I think is the thing we still have to push on.

Right? It's that moment of uncertainty by still so many that we have every right to be here and we can do exceptional work, right? And I've said this in other places, it's a radical idea that disabled scientists can be exceptional. That's still a radical idea. And that's what has to change.

>> Caroline: All right, yes, absolutely. So we're going to go ahead and go on to our third question here, which is how can people be proactive about establishing accessible and inclusive environments? And what infrastructure such as tools or cultures do we need to change and touch on for some of this and to include some of our audience and what people in our audience can do about all of this?

>> Nils: This is Nils Hakansson. One of the -- and this isn't a direct answer to the question,.

>> Inly, but one of the challenges that I have experienced and some colleagues have experienced is really getting buy in from the organization and the university that's kind of responsible for implementing things and spending the extra dollars the maybe make things accessible and universal design.

You know, there's -- you know, I have a love/hate relationship with that group. I mean, they've done some things which I think are great and at one point realized that as a post-doc in another university, all the rest rooms were either right handed or handed, so all the male rooms were kind of right handed. As a wheelchair rider, if you wanted to transfer onto the toilet or if you had a stroke, the ground bar was on the right side for the men's restrooms and the women's rooms were kind of the mirror image of that.

And realized that, okay, on the alternating floors, you could easily swap it around so that you do have a right handed restroom for, you know, men and women in the same building.

And I brought that up to our group, and they implemented that now in all of our new buildings and we're building a lot right now, which is great.

But the other side it is the notion that ADA compliance is accessibility. And the real user component is what makes the difference. And that's -- again, it's a wide variety of users.

And making the modifications is, you know -- there's a lot of resistance. And often the response is, well, it's ADA code. We're good to go. And so I think having enough critical mass of people say no, this isn't good or, hey, you know what, this is to code, but it's not useful, so I think that's part of, you know, our goal here, is to get enough people with disabilities involved to be able to then have that voice.

And my approach has always been to work with students. They listen to students more than faculty, which is great.

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>> Bonnie: This is Bonnie. Nils, I agree completely with everything you said. You know, I would add to that that, you know, we do need institutions of higher ed and academic research center to move from a posture of compliance in this space to one of, you know, promoting disability rights and disability justice, right?

And the pragmatic approaches that Nils just described. Right now in most spaces it is, it's just checking the boxes of legal compliance, if that. And that's not enough. And that doesn't situate someone for success, quite honestly.

The problem is, in my view, is that lots of leaders aren't attuned to these issues. And there's historical reasons for that. There's gaps in who is in leadership. There's infrequently people with disabilities in leadership positions advising these individuals of the community. So it takes Herculean efforts to champion these causes up to leadership.

And that's part of what I think has to change. That really needs to be the future, is to create a pathway where we have more diverse leadership that also includes people with disabilities in these settings so we can have really a holistic, more inclusive environment, and I think that's important.

I'll also add to what Nils said is it's important to consider the role of funding agencies in this too. You know, funders both can make decisions based on sort of what different universities and organizations are doing to promote disability inclusion, as well as to support projects and disabled researchers, right?

And I think there's a lot of opportunity left on the table right now to do this, and I think that's a path forward.

>> Caroline: Yeah, Theresa?

>> Dr. Edelman: Yeah, I just love the kind of richness of this conversation and all the different perspectives that are being contributed. And I think this is the perfect example of how we need many people with disabilities to contribute to planning, and the question is about being proactive, about establishing accessible and inclusive environments.

Like, are people with disabilities on the planning committee for buildings that are being built at your institution? Like, let's not wait until after the building is built to realize some of these things.

Like, if you access some -- like, one of the most valuable resources that institutions have are the disabled people that work and use the spaces around you, and, you know, tap into that resource and ask or invite people to participate in planning committees.

And not just one disabled person. Because my disability is a mobility disability. I can tell you, you know, how, you know -- the difficult -- things that are difficult for me to access, but I don't have a visual or hearing impairment, and so it's important to include people with other disabilities that can provide a unique perspective.

And as far as cultural changes that need to be made, nobody should be ashamed of acknowledging that they have a disability. And this in my talk is -- I what I allude to is being the harder thing to fix. I mean, we're -- you know, we're the STEM field. You know, we're curing cancer, and we are, you know, rolling out vaccines within a year, and we're sending, you know, billionaires out to space.

We can -- I mean, like, I'm starting to get energized. We can do this, right! We can build buildings that are accessible if we want to, right? If we want to.

We can do this. But the hardest thing to change is making it okay to admit that you have a disability, right?

The statistic that I shared that Dr. Swenor published about 1.2% of people reporting a disability, I

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don't believe it's 1.2% of people with a disability, that's the number of people that report it, and there's a number of people that don't report it because there's such a strong stigma that's associated with disabilities.

So, anyway, we can do this.

>> Rory: This is Rory. I'd like to jump in if I can. This has been a great discussion. What is your -- what are your thoughts about peer review and science? You know, I think they tell you about nothing -- about us without us in the disability community, but I've been in sciences in the area where actually almost everything is about us without us.

And I don't think, you know, if we take a page out of the book for women, at least at NIH, they haven't achieved, I don't think, what they deserved, but at least they've made their voice heard within the leadership, and I don't think we have. So I'd like to love to see what you think about that.

Part of my thought too is you can't really become a scientist unless you can get a grant and maintain grants.

>> Dr. Duerstock: I guess my thought on this topic is that, yeah, I think we're still in the infancy of thinking of how do we accommodate students with disabilities and how do we make sure we are compliant and this is a group that we need to nurture and, you know, try to include.

But, yeah, we're still -- we still have a long ways to, you know, reach the professors that are -- we want to be -- have with disabilities and the department heads. So right now, we aren't just looking at this is a group that needs assistance or charity. So I think we still have a long ways to incorporate that into STEM careers.

And, yeah, as a, you know, person with a disability, being a student with a disability was horrible. But once I could get my own students and my own grants, I could have them do all the things I always wanted to do as a student.

And it was great. And it's much nicer to be on this end of the spectrum as a professor with a disability than those trying to struggle to get to this position.

And that's unfortunately the case is now. And when we get to medicine, which we haven't really talked too much about, but there's core competencies that really make it impossible for a lot of people to ever even get into medical school.

When we have tons of examples of very successful physicians with disabilities, but they sustain disabilities after they got that MD or DVM or whatever. And they figured, okay, I'll get into radiology or psychiatry or they found their niche, but a lot of students aren't afforded those opportunities, unfortunately, to get to an area of success.

It's a struggle. It's a long road to hoe, and, you know, yeah, it's still -- still, I'm glad not to have to go through that again.

>> Bonnie: This is Bonnie. You know, I want to thank Theresa --

>> Caroline: Donee, buffer go, I think Nils had something to say.

>> Bonnie: My apologies, Nils. I didn't see your...

>> Nils: Actually, go ahead. Sorry. I'm still digesting what by was going to say.

>> Bonnie: Apologies. I don't see hands well on Zoom. So thanks, Theresa, for talking about the study we published. And you are exactly right. We believe that data, the percentage of NH funded researchers with disabilities is underreporting and that's part of -- I appreciate you making that point, but that's exactly what we need to change.

And Rory, to your point, peer review, I still struggle with it, admittedly. As a disabled researcher

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who studies disabilities equity, I can't even -- I've lost count of the number of times I've been told either in journal or on grant reviews that I'm biased because I am studying disability inequities and I myself have a disability.

And I just want you to think about what that means, right? It means that, one, that someone without a disabilities is not biased. No, that's wrong. Think about applying that to another group. I don't think we would do that. I hope we wouldn't do that right now.

Right? That has absolutely prevented me from getting grants, from getting manuscripts accepted in journals, and I'm sure it will continue. And you know, certainly I'm not going to pretend my science is always spot on or perfect. Right? There's -- I don't want to pretend that.

But I absolutely, as do many of my colleagues, and I'm sure many people on this call, contend with those real issues in peer review. I am public about my disability. I'm not hiding it from anyone. I align with what Theresa talked about, with disability pride. I have no shame. I write about it. In my bio sketch. So study section knows.

Yeah, I think it's a concern. It's an issue. I have been told that I would have been invited to give a talk, but there was concern that I couldn't travel independently. The list goes on and on. And this stacks up and adds up over time, and does have a net impact on an individual's career trajectory, opportunities for promotion.

I've certainly felt that. Right? This is real. But we don't talk about this. We don't think about this in our institutions, at funding agencies, of how to support the unique barriers to researchers with disabilities.

And I think this translate, and I just want to elevate, we're talking a lot about sensory and physical disabilities, but it's people who have chronic conditions, who are, you know, compromised, people with mental illness all included in this space.

And until we can get more researchers, more faculty with disabilities who at least are willing to be open, we're going to continue to perpetuate these gaps because the students don't have mentors. Right?

And I acutely feel that. And I think that's -- that's something we've got to think about, both sides of this equation, the learners and the mentors and the leaders. And I just think it's an urgent issue, so, Rory, I appreciate you elevating this. This is, I think, important to mention.

>> Caroline: Nils, you are ready? Have you fully digested your thoughts?

>> Nils: Well, it's changed a lot, quite a bit. Bonnie, thank you, that was -- you know, it's very, very moving. I personally have not experienced that, I guess. At least from the peer review side.

And I feel kind of ignorant now. I have actually had some fairly positive experiences through the National Science Foundation with a disability. They -- there's a group there that has been, I think, very proactive about bringing people with disabilities in. Ted Conway ran the charge program, disability and disability research engineering, yeah, I may have messed that up. Now it's DARE, disability and rehabilitation engineering group.

And I think that they actually work very proactively to bring somebody with a disabilities onto the panels so that they have that perspective. My experience there was always very positive and, you know, and it's an opportunity to, in a sense as well, guard that, no pun intended, that those fundings are actually being used for the intended purpose of disability related research.

Often you would get people with more biomedical research that were kind of looking at that because it's a smaller program, but to say, you know, well that might be better for the larger group, whereas this

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is much more of a focused opportunity for disability-specific work.

Other sides of things, sorry, my voice, I got to get some water here. The supplemental funds, and I think that that's a great way for people with disabilities or researchers to incorporate students with disabilities in research, is to -- and if there is accommodations needed, travel companions for conferences, those are -- there is funding available for that.

And I think it also, not only does it benefit the individuals who will be utilizing that funding, but it also let's the funding agency know that this is a need, and that there are people out there who are utilizing this and we are growing our population.

So I'll end there.

>> Caroline: Thank you so much, Nils. We have some amazing questions coming from the audience. One question is what are your thoughts on the impact of learning for students with disabilities, especially now relating to lab activities, we're moving to a more remote environment. How do you feel that transition has specifically impacted students with disabilities?

Yeah, Theresa?

>> Dr. Edelman: Yeah, that's a great question. So it's been teaching science labs for several years now and switched from -- I was fully -- teaching fully in-person before the pandemic and I now teach fully online.

I've been teaching both asynchronous as well as synchronous labs. I think that virtual learning has, you know, pros and cons. Sometimes people with disabilities have difficulties, you know, travelling and getting to a campus.

And so having a virtual option is great because it allows access to some people who otherwise wouldn't be able to participate in a lab course. However, it's important when doing things online that it's accessible for people, you know, with, you know, visual or hearing disabilities, that there's captioning in, you know, videos or -- and, you know, image descriptions, that documents are accessible.

So there's a -- you know, it's important to make sure that online learning is accessible for everybody.

One of the things that I did in the lab, microbiology lab that I was teaching with some of my colleagues is that we put together a lab kit that we sent home -- or that we shipped to students so that they could perform experiments at home.

And you know, those kinds of, you know, thinking outside the box are things that we can do. So I think that there's a lot that we can learn from the pandemic. A lot of people from the disability community have been asking for the ability to work remotely for a long time, and the pandemic has shown us that that is a very real possibility. In fact, a lot of companies are shifting a lot of their workforce to working from home.

And I think that we can also provide that sort of access through learning as well. But making sure that it's accessible.

>> Caroline: Absolutely, yeah. And Nils?

>> Nils: I think you meant Bonnie.

>> Caroline: Oh, yeah, or Bonnie, yeah. Bonnie, go ahead.

>> Bonnie: Yeah, thank you. I think that it has -- you know, I echo what Theresa has said, but I also want to add that it's opened up the faculty to teach our courses, faculty with disabilities, and that's been critical as well as faculty with lots of situations who are providing care for children or other family members and I think there's been a lot of discussion in the disability community in higher education, but in other spaces that we need to hold tight to these gains that we've gotten in this experience during the

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pandemic of remote and virtual learning and work.

There's real fear that we may completely move back to a model that excludes this option.

And for those that had access that they didn't have before and really benefited from this, that would be a huge mistake, right? A big miss. That would close a door that was opened. And I just want to urge everyone in the audience who may be in opportunities to think about these decisions to think carefully, right?

As we move forward hopefully at some point through the pandemic, to recognize that, you know, this has been an interesting natural experiment in lots of ways, but there have been some positives and this is a positive, I think, for lots of people in the disability community, as Theresa outlined, as long as it's prioritized.

And to go back to a model where this no longer exists will go back to a situation of exclusion.

>> Nils: If I can add. I do definitely see the benefit of the online versus in-person. The work in my lab is much more of a physical kind of thing. With the pandemic, we were able to have a smaller group and, you know, we've sort of divided into smaller groups so that it was kind of -- it kind of fit the university policy of no more than six in a certain size space.

But we can also videotape things and have, you know, visual experiments and that certainly only helps a component of the population. We did not, in my current situation, have a need for like a closed captioning or a descriptive audio, but that certainly could be something that could be done as well, I think.

And as Bonnie said, you know, the hybrid approach or the virtual environments really do provide, I think, you know, for me as a faculty member with a disability, an opportunity to, you know, if I'm not feeling well or if I've got three different things going on that I can't get across campus to the classroom or if it's a really bad weather day that I don't want to sit out in the cold and wait for a bus or take the risk of driving on my own, I can Zoom in and we can have our lecture.

And maybe not the lab activity, but at least certainly the communication. And maybe pursue other options. You know, there are other -- we did a workshop with a larger group earlier last year and worked with some of the assistive technology providers, and they've really stressed the benefit of having an option for somebody who may need the recline every 20 minutes, that you can't necessarily do that very easily in the office.

Or if you, you know -- you know, want to have the ability to, I mean, have a meeting like we're having right now, this would not necessarily be possible to the extent that we have 200 people all congregate in, you know, Washington or Kansas City or something like that.

So this benefit, I think, will -- you know, it does certainly make it a lot easier for me, and I'm sure for others who are, you know, participating can see the advantages, and we did hear locally that, you know, a group of engineers and one of the aircraft manufacturing companies, the manager is saying that they're more productive now that they're working at home.

And so hopefully companies will see the value of it as well and work to maintain it.

>> Caroline: Great, yeah, and Theresa, you had a comment?

>> Dr. Edelman: It's more just a plug in there. In my talk I mentioned being able to access scientific meetings virtually has been amazing. And for people who -- with disabilities who have difficulties travelling, allowing for that to be an option, to be able to participate virtually, have access to, you know, posters and presentations and, you know, panel discussions is great.

I mean, and I think that, you know, I would hate, like, Bonnie has said, I would hate to see these kinds

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of opportunities disappear when we, you know, go back to, quote, unquote, normal.

>> Caroline: Thank you so much, Theresa.

And I just wanted to add to that, as far as deaf students who have been learning remotely, we have actually seen a decrease in the number of students enrolling in our lab courses.

You know, we'll see everyone, you know, as far as -- which has kind of been interesting, because in Zoom, we'll have, like, six students, you know, and we can actually see each other more clearly in that kind of a way.

So we've just been trying to navigate, you know, doing Zoom and sending the lab links, you know, to students, you know, decreasing the size of our classes has really been an accommodation to be able to help students learn virtually.

To just have less visual stimulation going on. And then for virtual meetings, we actually, myself, I actually prefer the virtual meetings because it's very fine -- hard to find interpreters who specialize in the field of STEM. But now with virtual options, that opens it up to any interpreter in the entire country. So now I can have an interpreter who specializes in the field of STEM who might be in another state but is able to join virtually and provide that, you know, more technical support and is knowledgeable of our field.

And we're also, you know, able to have more of those water cooler conversations that I can participate in the chat and things like that. That I just -- I am not normally privy to in-person conversations or with in-person conferences. So, yeah, I just wanted to add that.

I did want to go ahead and add one more question from the audience, which is what are your thoughts on the inclusion of data, accessibility of data?

Bonnie, yeah, please go ahead.

>> Bonnie: I think Brad was first. Go ahead, Brad, sorry.

>> Dr. Duerstock: Yeah, I think that's a great question, because we're seeing data as being so integral in how we discuss findings and how we interpret findings.

You know, data sciences, the term was really not a thing not too long ago, and so now everything is really a lot of data science.

And, yeah, I think how we interpret data, how we capture data, we really need to look at that. I made a comment that we've been so visual centric in our science data for how long, that how much are we missing because we're just looking at data in terms of collection from a visual aspect modality.

But then of course when it comes to access, how do we present that data? And I don't know if I have great answers to those questions. But we definitely need to re-evaluate that. Note taking has long been a problem with a lot of people with disabilities, and how do we collect that data. I think there's new technologies out there to allow us to collect it in digital forms and process it in different ways.

And so I find that very exciting, you know, in the classroom you can record the classroom, conversations. But, yeah, I see that really as a new frontier in accessibility, is how do we get information.

>> Caroline: Yes, go ahead, Bonnie.

>> Bonnie: Yeah, this is Bonnie. Thank you. As someone with a visual disability and epidemiologist who thinks about data far too much, this is a great question, so thank you for whoever asked it. Data accessibility is a pervasive problem and it's not just researchers and trainees, it's a problem for the general public, I think that's been played out throughout the pandemic.

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As I work with students and my own career, it's the software to installed data that isn't always accessible, the tools, the data collection components in tools aren't always accessible, and think about what that means for both the researchers with disabilities and the inclusion of people in collecting data from people with disabilities.

Who may be preferentially excluded then. As Brad said, when you're sharing data it, it tends to be a visual exercise, and you can miss a lot of information when that's not made accessible with alt text and universal design practices.

Journals do not adopt this mostly. And that's a challenge for folks like me who have a visual disability and many other types of disabilities in getting content that's critical, again, for your career success and understanding your field.

But I also argue that it's critical for our job as researchers to work with the public, and our goal shouldn't just be to publish in scientific articles and speak at conferences, but to sort of go beyond that and have impact in the world. I believe in removing barriers to data, to remove data gate keeping and accessibility is critical to that.

So, you know, in the pandemic, there was a lot of information and continues to be coming out very fast. You know, think of the curves, the pandemic curves. They're not always very accessible, yet people use those to make decisions, personal and family and, you know, otherwise.

And if you don't have that content or that information, it's -- it's your kind -- you're kind of left behind. It's challenge. So I think this idea of, again, universal design, inclusion and accessibility has to be everywhere. And data really is critical. Data is part of this component, both for the researcher side and also for the general public.

>> Caroline: Wow, Bonnie, that is very well said. And it's a very interesting perspective, because we talk -- in my perspective, we talk about the audio portions of it and software translations from audio to visual, so it's interesting to hear about your perspective per the opposite, talking about how to make visual things more audio accessible.

And showing data in different ways so that we can learn something new. For example, if something listens to something, someone listens to something and then maybe they see something differently, where is the disconnect there? Is the disconnect in the audio information or the visual information?

So that's something that we can take advantage of. So we have six minutes remaining. So I will ask one final question. Let me pull it up here. Okay, so one of the chat questions, is it possible to speak to how we can have more students involved -- students with disabilities involved with science and lab careers?

Nils?

>> Nils: Yeah, thank you. There's -- let me get rid of the hand here. You know, there have been several programs over the years that have worked specifically on this. AAAS had the entry point, which was actually recruiting people with disabilities in high school, and bringing them through the sort of the STEM pipeline and really focusing on internships in government agencies, so NASA, for instance was one.

I actually learned about it as a grad student. I somehow missed the boat. I seem to do that a lot too much. But it was a great opportunity, I think, for people -- for the government organizations to really channel -- or develop opportunities and to work with students with disabilities to show opportunity -- well, potential placement and then, you know, also to see people move into those jobs, it would sort of create this reoccurring system.

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There's, I think, a lot of funding through the National Science Foundation, the includes grants, the advance grants, so I'm happy to see that, and I'd like to see more. I'll stop there.

>> Caroline: Great. And Theresa, we'll go ahead and have you close out our comments, and then we'll have our final wrap-up for today.

>> Dr. Edelman: Yeah, wow, that's a big load to carry.

I guess what -- I think mentorship programs are really great because they can connect people -- students with disabilities to mentors with disabilities who have, you know, maybe experienced the same thing or somebody to reach out and connect with if you're, you know, encountering some barrier that you're struggling with.

I think looking back on my career, it would have been really helpful if I had a mentor that was disabled and that I could receive support from that end. I'm, you know -- OPI and the scholarships and STEM mentorship program, and one of the things I've learned through that program is how important it is to have many mentors, not just a research mentor, but also somebody, you know, who that -- that maybe can relate to one of your identities that you hold.

But another thing I want to point out is that this work shouldn't just rest on the shoulders of people with disabilities. Like, you shouldn't just wait for somebody with a disability to start a mentorship program. You know, learn about, you know, opportunities or, you know, people who don't have disabilities and faculty and, you know, PIs, like, bring awareness to disability to your campus.

Just talking about it is huge. Because, like, it makes you not feel like nobody notices that you're disabled. I mean, there were never conversations throughout my career about disability. And just everybody, you know, pay attention to disability and include it in your conversation.

>> Caroline: Thank you, Theresa. I'm afraid we have to end our conversation. And wow, what an excellent conversation today touching on so many different topics, covering lab accessibility, inclusion in environment and not just in the STEM career fields, but in a broader sense.

The benefits of disabilities to the STEM workplace, and also how we can provide good virtual experiences for students with disabilities. And lastly, how we need to encourage more students to get into STEM fields so that we can develop more of those mentorship programs, because many of us are now leading those programs because of our experience.

So this is the second of five conversations in this series, so our next conversation will take place on Thursday, February 10th, from 10:30 a.m. to noon and we'll focus specifically on recommendations to improve accessibility and inclusion in the context of field work.

And as a researcher myself and a field worker myself, I am very much eager to be a part of that conversation and to -- for that conversation to take place. So thank you all for joining us, and more information about our next series will be posted on the series website on Slido.

And this web cast, again, will be recorded and posted on Slido as well. That holds true for the remainder of our series as well, those series will be recorded for your pleased viewing at a later time if necessary. So thank you again for the wonderful conversation from you guys as panelists and for everybody that was able to join us today.

Thank you so much.