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 keynote talk by Dr. Theresa Edelman

NOTE: This is an unedited transcript of a keynote presentation prepared for the Accessibility and Inclusion in STEM conversation Series held on January 25, 2022. The transcript was prepared by Katalyn Voss 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.

Hello my name is Dr. Theresa Edelman. I use she/her pronoun. I'm a white woman with brown eyes and long brown hair wearing a blue sweater. Located behind me on one side is a window and door and on the other side is the bookshelf with some books on it. I'd like to thank the National Academies of Science, Engineering, and Medicine and the organizers of this conversation series for giving me the opportunity to speak today as well as my PhD thesis advisor, Dr. Anne Rugby who nominated me to be a part of this conversation series. I'd also like to acknowledge those who championed the disability rights movement, including Judy Heumann and Ed Roberts, who paved the way to make it possible for a disabled woman such as myself to attend a mainstream public school and achieve a career in the STEM field.

Before I continue, I want to acknowledge I am only one person. My experience is my experience alone. I don't represent all disabled people, and I don't represent all disabled scientists. I also do not represent all people with dwarfism. I represent myself. Like Dr. Okanlami said last month, I am an “n” of one.

I earned my Ph.D at the University of Minnesota in molecular biology and genetics and now teach biology at Minneapolis Community and Technical College. I amCo-PI for a STEM mentorship program at Minneapolis College.

And as part of disability advocacy, I work to bring awareness to disability and ableism to the Minnesota state colleges and universities system.

I am also part of the Minnesota Partners in Policy Making disability leadership training program this year.

I was born with a genetic condition called achondroplasia, which is the most common form of dwarfism.

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Growing up, I was the only disabled person in my immediate family; however, today disability is the norm in my vibrant household. My husband and I as well as our four beautiful children all have the same type of dwarfism. The picture shown here is of the six of us standing in front of the steps of our house. My husband and I are standing in the back. We are both white with brown hair and stand about four feet tall. Our four children are standing in front of us in bare feet. Two of our children are boys and two of our children are girls. Three of our children are ethnically Chinese and one is white.

Growing up, I always tried to fit in and not draw attention to myself, feeling ashamed of my disability; however, I've grown to be more confident in who I am. Instead of asking myself and my family to fit into an inaccessible world, I'm asking the world to change for me, my family, and the disability community to become more accessible and inclusive.

The title of this conversation series is Leading Practices for Accessibility Inclusion, so I wanted to take a moment to discuss these terms. Accessibility, according to the U.S. Department of Education, is when a person with a disability is afforded the opportunity to acquire the same information, engage in the same interactions, and enjoy the same services as a person without a disability.

Inclusion, on the other hand, goes one step or many steps further. The U.S. Department of Housing and Urban Development defines inclusion as when people are valued, respected, and supported.

In order to be supported you need to have access, you need to have the same opportunities, the same interactions, and enjoy the same services as everybody else. Accessibility is oftentimes the first step towards reaching inclusion; however, inclusion is more difficult because it requires that people are valued and respected. Unfortunately, that's difficult to achieve because of the bias that exists towards people who appear or function differently.

I want to tell you about a story when I learned about the bias that existed towards me. Growing up, my mom was my strongest advocate. She would make sure I had the accommodations I needed to access my school environment, and as I got older I became more involved in this process, but she would always be there to support me.

This is a picture of my mom. We are posed in front of a Christmas display. My mom is on the left. She is a white, average-heighted woman with shoulder length brown hair and is kneeling down to my level with her arm around me. I'm standing on the right, my brown hair pulled back into a ponytail.

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During high school, I was starting to develop my interest in science. One year, I was planning to take chemistry class and my mom had a conversation with my chemistry teacher, likely about my disability and accommodations. My soon-to-be chemistry teacher shared with her that he didn't think I was going to do well in his class based on the knowledge that I was a female with a disability, dwarfism. I remember my mom and I talking about how ridiculous that comment was and how I would prove them wrong, which I did by getting one of the top grades in the class and moving on to get a degree in biochemistry. However that comment has always stuck with me: that I'm not expected to do well.

While that's a ridiculous comment, there is some truth in it, and in that that is the bias that exists.

That moment was profound for me because it opened my eyes to the bias that I was up against going forward.

Bias is a harder thing to push against and overcome than any inaccessible environment. Once I moved away to college, I was responsible for my own advocacy. I avoided any accommodation because of the stigma that accompanied them. I believed that drawing attention to my disability would give people a reason to determine that I was unqualified or incapable.

A comment such as that is powerful enough to derail somebody from achieving a career in whatever field they're trying to move into. Fortunately for me, it didn't stop me; however, disabled people are significantly underrepresented in STEM.

According to the Center for Disease Control and Prevention, 25 percent of adults report having a disability.

In 2019, Meeks, et. al reported that 4.9% of medical students in allopathic medicine reported a disability. NSF has noted that 8.6% of doctorate recipients in science and engineering report a disability, and even more concerning, NIH grant applicants and awardees reporting a disability has declined from 1.9% in 2008 to 1.2% in 2018.

This is where we are and this needs to change. The lack of representation from those with disabilities diminishes the field because it prevents input from people who bring a unique and valuable perspective. Disabled people encounter challenges every day that require sophisticated problem solving and creativity.

These skill sets are an asset that is significantly under-utilized.

There are many barriers that can prevent somebody with a disability from accessing an environment in a STEM field.

In order to make something inaccessible become accessible, an accommodation is required. Not only is the inaccessible environment itself a barrier, but the process involved in acquiring an accommodation is also a barrier.

In order to ask for an accommodation, a person with a disability needs to be able to self-advocate. For myself, that was difficult because I didn't want to draw attention to my disability.

For people who feel empowered to self-advocate, they need to know who to ask for an accommodation. Many universities have disability resource centers on campus; however, they usually cater towards undergraduate students.

For other people, such as graduate students, postdocs, faculty, and staff, it's less clear of who to ask for an accommodation.

In order to ask for an accommodation, you also need to disclose your disability. For myself, my disability is visible; however, many people have non-apparent disabilities and choose not to disclose because of the stigma that is surrounding disability.

You also have to provide documentation. Often documentation is usually in the form of a doctor's note that requires a diagnosis as well as a medical appointment that costs money and health insurance.

You also have to know what to ask for and sometimes that's not very clear, especially if you're starting a new job or you're working from one environment to a next or from one tool to a different tool.

Also some many people may not even know what they can ask for.

And finally the accommodation request needs to be granted.

There is usually a department or agency involved in granting requests. They are the gatekeepers to providing accommodation and they get to determine what a reasonable accommodation is.

One way people with disabilities can access the things they need is through the use of assistive technology. Assistive technology is used by disabled people to perform functions that are otherwise difficult or impossible to do. Some examples include a wheelchair, screen reader, or hearing aid. The assistive technology that I use most is a step stool.

Most research labs or lab benches come up to about my shoulder, so that's a surface that's difficult for me to function at.

When I step up on a stool, it brings me up to the same level of the lab bench.

The picture here shows me standing on the first step of a two-step stool the bench comes up to about my waist. I'm wearing gloves and a mask and I'm lighting a bunsen burner.

There's oftentimes a stigma that is associated with assistive technology that I'd like to address. When someone requires a device to perform a task, onlookers often assume that the disabled person cannot perform the task as well or as safely as an able-bodied person. For example, when I step up on a stool it's common for people to tell me to be careful.

An able-bodied person is not used to interacting with that device to the level that I am. For example, most people use the stool on occasion, probably not every day. I, on the other hand, step up and down from a stool probably 40 to 50 times a day. I'm very familiar with the stools I use. I know where the edge of the stool is and I know how far I have to kind of lean over, how far I can lean over before I become unstable. I'm aware of my limitations and I know what I can do safely.

It is important that when people with disabilities come into a workspace and are using a device that the stigma or assumption that they are not functioning as well or as safely needs to be addressed and cannot prevent somebody with a disability from working and functioning in a lab.

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Assistive technology is one way to make the world accessible to a person with a disability; however what if we made things accessible in the first place? This would remove the need for an accommodation and make spaces more inclusive for disabled people.

Universal design is a way to do that. Universal design creates tools and spaces for everyone. It is the design of an environment or product so that it can be accessed used and understood by all people regardless of their age, size, ability, or disability. When universal design principles are used you're designing spaces and tools for everyone, not just the average user. Examples include ramps, automatic doors, closed captions. These features not only provide access to people with disabilities but also benefit the average user. A ramp and automatic door allows a person who uses a wheelchair to enter a space. It also allows somebody pushing a cart full of luggage or a child in a stroller to move through a door as well. Closed captions can be useful for a person who has a hearing disability or I oftentimes benefit from closed captions when I'm watching videos on my phone early in the morning when the rest of my household is sleeping and I don't want to have my volume on. Universal design was originally with the intent of making architecture more accessible but has also moved into the world of teaching through universal design for learning.

One piece of universally designed equipment that I benefited from when I was working in the research lab was a height-adjustable lab bench. In the picture shown here on the left I'm working on the bench; however the difference between this picture and the one that I showed you earlier is that I'm no longer standing on a stool. My feet are planted on the floor, the bench comes up to about my waist, and I'm able to use it and do whatever I need on the surface. I'm wearing a mask and gloves in this picture and I'm holding a pipette and aliquot a liquid into tubes that are positioned in a rack.

For me, this was a really powerful moment. I remember on the first day I joined my Ph.D lab I was standing in the lab and my thesis advisor walked in and said, "let's lower your bench."

I was taken aback because that had never occurred to me. I hadn't even noticed that the benches were adjustable because I was just used to using a lab to access the bench. Within 10 to 15 minutes the bench had been lowered to my height. The technology is actually quite simple. In the picture here on the right there are two legs of two different tables arranged next to each other. The one on the left is lowered to the lowest level, which is a height that works well for me. The one on the right is at a height higher up. It can be adjusted just by pulling the pin out raising the bench and replacing the pin in the leg of the table.

The great thing about universally designed equipment is that it doesn't require an accommodation. For me, this was powerful because I didn't want to self-advocate; however there were a number of things that needed to happen in order to make this a possibility and a reality.

First, people needed to design the equipment. Somebody designed a table that could be adjusted to various heights. Secondly, the people or the group that was responsible for choosing the equipment and the furnishings for the lab when it was designed needed to choose that equipment. And third of all, my thesis advisor pointed out we could lower it. Nothing was required from me.

Another example of ways that I access the lab using both assistive technology and universal design is using one of the microscopes that I spend hours and hours at. This is a dissecting fluorescent microscope. I'm sitting at a height adjustable chair and at the height in which I can view the microscope through the ocular. The chair can adjust but the oculars can also adjust not just left and right, but also up and down.

On this microscope there was a foot pedal, and since my legs are short I can't reach the foot pedal, so one thing I did to work around that was to take a large catalog that nobody was using in the lab and put it on top of the pedal to hold the pedal down. Then you can see I'm reaching around to the back of the microscope. On the right hand side, there's a dial to increase and decrease the intensity of the light. Rather than using the foot pedal, I just use the adjustment knob to turn the light off and on.

So I've shown you a few examples of how universal design can be beneficial, but there's many other ways. I have a physical mobility disability, but disability is diverse. There are people with all sorts of needs and so it's important to pay attention to other disabilities as well.

So some other suggestions on how to make a lab universally designed is through first making sure that the entrances to the building and the lab are accessible as well as the bathrooms. These are oftentimes things that need to be considered when planning and building labs. The best way to work towards making spaces accessible and inclusive is to include people with disabilities on building and lab design committees.

Other ways to make labs accessible are to make sure that the labs are uncluttered with clear and wide aisles that can be easily moved through if somebody is using a wheelchair or someone like myself who is pushing a stool around.

The adjustable tables that were in the lab that I used they were not secured to the floor so they could also be slid over a little bit if the aisle needed to be widened.

So adjustable lab benches and chairs are a good option which I've mentioned. There's also electronic and ergonomic pipettes that can be helpful for somebody with difficulty fine motor control. Plastic beakers and graduated cylinders are useful. When I was working in the lab, I had a selection of both glass and plastic containers, and I oftentimes gravitated towards the plastic ones because they were lighter weight, the graduations were oftentimes raised, and so they were easier to grip and I didn't have to worry about breaking them.

Fume hoods are also difficult to navigate because there's a flammable cabinet down below and then the glass shield.

There are portable ductless options that can be put on a height adjustable table and made accessible for somebody who uses a wheelchair or for somebody who's short stature like myself.

Flexible electrical water and gas connections allow equipment to be brought closer and more usable if reach is a difficulty. Also a lab assistant or lab partner is a great option for a person with a disability who has difficulties with specific tasks, which is something we do all the time. I remember there were certain people that were better at certain tasks and we oftentimes delegated to those lab personnel.

Accessible documents and electronic lab notebooks can be useful for people who use screen reader or for people who have difficulties writing and typing is easier.

Additionally, verbal or written instructions can be beneficial for people with visual or hearing disabilities. Now, this is just a list short list that I have included; however, I want to point out that Dr. Burgstahler has a great resource called "Making Science Labs Accessible to Students with Disabilities". This resource has a much more comprehensive list and has suggestions broken down into types of disabilities.

So for me, once I had my lab space set up to a way that I could function in it, my lab bench was lowered, things were arranged where I could reach them, stools were in places where I needed them. I could function quite well and quite efficiently in the lab; however one of the things that was very difficult for me as a scientist was attending meetings and social events. It's important as a field to pay attention to these things, especially when these events are important for advancement within the field, inaccessible meetings and social events can prevent people with disabilities from making progress.

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A few examples from my personal experience. Graduate school interviews included social events at bars to interact and get to know some of the current graduate students. It was mentioned last month at on the discussion panel how inaccessible bars are, and I want to reiterate that they are very inaccessible. Not only are they over stimulating in a sensory fashion, in the sensory way, but for a person with a mobility disability they can be hard to navigate because they're crowded. The tables are at a high height as well as the chairs and the bathrooms are oftentimes difficult to maneuver in.

People are also not always on their best behavior in bars. For a person with a visible disability, such as myself, that can feel unsafe.

Also for people who are in recovery, events that are at bars is not a supportive environment.

Grad school interviews also included dinners at faculty's houses, which were really hospitable, however oftentimes people's homes are not accessible, and so it's important to make sure that there are accessible options for events such as this.

Research meetings were probably the most difficult thing for me to navigate in my research career.

I attended a research meeting every year and the meeting that I attended most frequently was held on a large university campus. Most of the talks during the day were located far apart. Sometimes I needed to walk a half a mile or more to get from one talk to the next and had about five or ten minutes to do so.

That was a huge barrier for me and I ended up choosing talks that were within close proximity to one another rather than the ones that related to the topics I was most interested in.

Poster sessions were also physically difficult to navigate. The image here on the right is an aerial view of a poster session than I attended.

In this image you can see that the event is held in a large sports arena. There are aisles and aisles of posters and a large crowd of people. Navigating through this space with a mobility disability was difficult.

Something else I want to draw your attention to is the height of these posters.

For an average-heighted person, these posters are at least halfway above their heads. For me, I come up to about the bottom of these poster boards. These posters are almost entirely above my head. Not only is that difficult to look up to and read, but looking up and walking around for an extended period of time caused extensive strain to my back to the point where I could barely walk. Ialso presented posters at these meetings and couldn't even point to things on my poster. The first time I presented, it was difficult to present because I couldn't point to anything. Eventually, I started bringing a laser pointer so that I could point to things on my poster.

Social hours were usually hosted after a poster session. If I could physically manage it, it was difficult too because there was usually no seating available or very limited seating. During the pandemic, I attended a two-day virtual symposium. It was the most comfortable meeting I had ever attended because I could sit at my computer and click on links to go to different talks, discussion panels or breakout session. I could choose to attend the activities that I was most interested in rather than worrying about how much my body would hurt.

Virtual options are a great way to provide some accessibility to the disabled community but it's also important to make sure that in-person meetings are accessible. Paying attention to the location of events is important. If events cannot be held near one another then make sure that there's accessible transportation available.

Poster sessions can be made accessible by posting posters and making them available online orproviding printouts to people who have difficulties viewing the poster. Social hours can also be made accessible by hosting them in areas that are easy to navigate and maneuver through and also providing ample and a variety of seating options.

So as I end my talk I want to revisit the statistic that I shared with you earlier that NIH applicants and awardees reporting a disability has been on the decline. In 2018, only 1.2% of people who received NIH funding reported a disability.

Let's work to change this. Most of my life, I viewed my disability as a burden that was inconvenient to accommodate for; however I’ve come to realize that my disability is in fact an asset because it gives me a unique perspective that others don't have. I’m creative, imaginative, adaptable, sympathetic, and determined.

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Providing accessibility and inclusion to the disability community is not only the right thing to do but it's an investment into a level of ingenuity and creativity that we're missing out on.

I encourage you to continue this conversation at your next departmental or committee meeting. Identify at least one thing that you can change to make the spaces that you have power over to be more accessible and inclusive.

Here's a list of resources that I have found that are useful.

This first one is a resource by Dr. Burghstahler, “Making Science Labs Accessible to Students with Disabilities.” The next one is a resource from the University of Minnesota on creating accessible and inclusive meetings and events, and the next one is a book on creating a culture of accessibility in the sciences.

I want to end by thanking the organizers for allowing me to be a part of this conversation that has a goal in mind of making change going forward. Being part of this conversation is meaningful to me because it has allowed me to use my voice and advocate for those coming after me. In honor of those who went before me, I would love to continue this conversation with anybody who is interested so I’ve included my email address here: teresa.edelman@minneapolis.edu

I look forward to the conversations that are going to happen in the future. Thank you so much for listening.