



AMERICAN  
PSYCHOLOGICAL  
ASSOCIATION

## ESSENTIAL SCIENCE CONVERSATIONS:

### BARRIERS FOR INDIVIDUALS WITH DISABILITIES IN THE SCIENTIFIC WORKFORCE: CURRENT DATA AND RECOMMENDATIONS FOR A MORE INCLUSIVE FIELD

(SEPTEMBER 12, 2023)

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#### TRANSCRIPT

**Dr. Mia Smith-Bynum:** Hello, hello, hello. Welcome to our webinar today, the APA Essential Science Conversations. My name is Mia Smith-Bynum. I'm professor and chair of the Department of Family Science at the University of Maryland. We are fortunate to have a very special topic for today's webinar, and this title is *Barriers for Individuals with Disabilities in the Scientific Workforce: Current Data and Recommendations for a More Inclusive Field*.

I want to begin by posing this question to our attendees. What are the challenges for scientists who are managing a research career while also managing a disability? People with disabilities make up over 27% of the US population, and yet they're severely underrepresented in both psychological science and the larger scientific workforce. A major barrier to entering and succeeding in the workforce is ableism, that is "stereotyping, prejudice, discrimination, and social oppression towards people with disabilities." Quoted from one of our panelists today.

A recent NIH report calls attention to the underrepresentation in barriers faced by individuals with disabilities in the biomedical and behavioral research workforce. We also are fortunate to have this report provide recommendations for making the workforce more inclusive.

This webinar is also a space where panelists and audience members can engage in open dialogues about emerging topics within the psychological science community. During this webinar, our colleagues here at the association who are assisting me with managing this event, they will put various links in the chat and other information to supplement our discussion and will help you to access resources that are relevant to this topic. Because we're live, I'm going to step away from one moment and close my door so that we're not disturbed during this session. Excuse me.

[pause 00:02:11]

**Dr. Mia Smith-Bynum:** The benefits of Zoom. Thank you for your patience. Now to our panelists. A bit of housekeeping. Please submit your questions or comments using the tools on your available Zoom bar. Type a question into the Q&A tool onto the webinar control panel. If you're having issues with viewing or hearing the webinar, log out and dial in using the information in your confirmation email. We'd also like to note that with the assistance of our guest speaker, we're going to be showing a slide deck that is largely 508-compliant. We will be able to make that slide deck available to attendees who would like to have a copy. Pay attention to your email after this webinar wraps.

Now we have our first presenter, Dr. Steven Barnett. Dr. Steven Barnett serves as the director of the Rochester Prevention Research Center: National Center for Deaf Health Research at the University of Rochester, and Professor of Family Science and Public Health Sciences. His academic specialty focuses on health, healthcare research with populations of deaf American sign

language or ASL users, people with hearing loss in their families and communities. Next up, and also the scientist who I quoted in our introduction, is Dr. Kathleen Bogart.

Dr. Bogart is an associate professor of psychology and director of the Disability Social Interaction Lab at Oregon State University. She's a social health psychologist specializing in ableism, disability, and rare disorders such as facial paralysis. She's also the co-founder of the Disability Advocacy and Research Network, or DARN, for psychologists and those who have and are specialized in disability research and their allies.

We're fortunate to have Dr. Alison Cernich, who is the current Deputy Director of the Eunice Kennedy Schreiber National Institute of Child Health and Human Development, or NICHD. She works to support the institute's mission to lead research and training to understand human development, improve reproductive health, enhance the lives of children, adolescents, and optimized abilities for all.

Next, we also have Dr. Lisa Iezzoni. Dr. Iezzoni is Professor of Medicine with Harvard Medical School where she is based at the Health Policy Research Center, Morgan Institute, Massachusetts General Hospital. She's conducted numerous studies examining healthcare experiences of persons with disability, focusing on primary, reproductive health, and cancer care.

Last but not least is Dr. Bonnie Swenor. Dr. Swenor is associate professor of the Johns Hopkins School of Nursing and holds joint appointments at Hopkins School of Medicine and Hopkins Bloomberg School of Public Health. She's the founder and director of Johns Hopkins Disability Health Research Center, which aims to shift the paradigm from living with a disability to thriving with a disability.

All righty. Let's have an essential science conversation. I'm going to stop the screen share for a moment so I can switch out to Dr. Cernich's slide deck. Wow, we see all these cool places in the chat. Welcome. Thank you so much for joining us. All right, Alison, once I resume this screen share, you just give me a verbal cue when you'd like for me to advance your slides.

**Dr. Alison Cernich:** Thanks so much, Mia. I appreciate it.

**Dr. Mia Smith-Bynum:** Okay. Where in the world is the share button? [chuckles] There we go. All righty. A moment. Okay. Take it away.

**Dr. Alison Cernich:** Thank you so much, and thanks for the opportunity. Just by way of introduction, for those of you who appreciate visual descriptions, I am a middle-aged white woman with brown hair. I'm wearing a black and sort of-- I don't know, rose gray floral top. I am wearing headphones so that you can hear me better and I can hear you better. I want to thank APA for hosting this webinar. It's been a real honor to be part of this. Next slide, please.

I think many of you are aware that we need to do better at including people with disabilities or disabled persons. I am going to use those interchangeably throughout my presentation knowing that the community often differs in the way that they like to identify themselves, and so please bear with me as I do this. We do not benefit with respect to research when we exclude people, whether that be minority groups, whether that be pregnant lactating people, which is a group that I also work a great deal with, or people with disabilities. They wind up bearing most of the cost.

When we entered into, for example, the COVID period for us in the pandemic, we really lacked evidence for some of these populations, and we had difficulty reaching them and including them in

trials. Most of what we know about what NIH funds, for example, in this area, is that less than 7% of the NIH funding that's attributed to disability is really about the experience of a person with disability in the health space. Much of it is really related to disease-based research and thinking about how to either prevent that disease or prevent the secondary effects of that disease and then that follow-on in terms of contributing to disability for the individual.

There's also no data right now on the active inclusion of persons with disability in NIH-funded research. We don't collect this data. We know that there are a number of executive and legislative mandates that set the standards for data collection and that prohibit discrimination based on disability. I also just want to shout out my colleagues at HHS, particularly Assistant Secretary Barkoff, who's acting right now, who has really championed and got a new proposed role on Section 504 strengthening the civil rights protections for people with disabilities. Next slide, please.

Why does this matter? Our obligation as the NIH is to support research that is representative of the US population. Honestly, people with disabilities make up a very large part of the US population, with estimates up to 27% of the US population. Healthcare costs for this population are about 4.8 times higher than the non-disabled population. Often our public health resources are tied to evidence of health needs, disparities, and inequities.

The other thing is for specific interventions, therapeutics, devices, and protocols, we don't understand the safety, efficacy, effectiveness for persons with disability. I will call out my colleague Dr. Theresa Cruz, who's been working with the National Institute of Biomedical Imaging and Bioengineering. For example, the COVID point-of-care test really didn't include accessibility as part of their design in the beginning, and she's been working with that institute on an accessibility initiative, so making sure that that happens. We just can't improve what we do not measure, and so we have to do a better job of measuring for disabled people. Next slide, please.

Why do we have this underrepresentation? The first is that we have an ableist perspective. There's an assumption that people with disabilities are inferior or inadequate. It leads to discrimination and social prejudice. There's a lot of assumptions about quality of life or that there's a need to protect people with disabilities when we could maybe better protect them through research.

There's the presumptive of the medical model, meaning that we really are looking at the medical condition and not the person as a whole. There's an assumption that the need for accommodations would increase the cost and complexity of the research or impact its feasibility. We also make assumptions that people with disability introduce what we would call noise. That there are heterogeneous characteristics that make data messy. Next slide. Next slide, please.

We need to make this different. We had the benefit in these esteemed panelists and colleagues that they are here today. The advisory committee, the director had a working group on diversity, a subgroup on individuals with disabilities who provided a roadmap for NIH to address disability and ensure inclusion of disability inclusion. They made some suggestions, and I gave some resources to APA to share. We are looking at updating our mission statement. We have established a disability equity and access coordination committee. We do have the development of an NIH-wide effort to address some of this structural ableism and promote disability inclusion, and we're also looking at this as core for our DEIA efforts.

We also published a strategic plan for diversity, equity, inclusion, and accessibility. That's here, and I've shared that link with APA to share with all of you, and making sure that our training

programs, our communication programs, our policies, and our structures are anti-ableist. That's going to be core to our DEIA efforts. Next slide, please.

First off, our mission statement. I just want to make you all aware, and these links here are going to be provided to you. This is our current mission statement, to seek fundamental knowledge about the nature and behavioral living systems and the application of that knowledge to enhance health, length, and life, and reduce illness and disability. We are proposing this to say now apply that knowledge to optimize health and prevent reduced illness for all people.

This is open for public comment if you have things to share about whether you like this adaptation or not. What we don't want to do is have people with disability feel like they need to be reduced or eliminated. That was our previous mission statement. I want to call out David Rice, who I think is on this call relating the charge to change it the first time, but I think we can do more. Please take this opportunity to put in your input on our mission overall as the NIH. Next slide, please.

This will probably come up at some point, but there was a council working group report from the National Advisory Council on Minority Health and Health Disparities this past September. There was a consideration as to whether or not as recommended by the ACD working group, the advisory committee, the director working group on disability to consider people with disabilities as a health disparities group.

This is an official designation that encourages the work in this area to see what the health disparities are for the disabilities community. The working group for the director there recommended against the designation and the decision from the director, he has to consult with the director of AHRQ on this decision. That is pending. This is a recommendation to their council, not a final decision, and I have in there the email address if you have any queries or responses about this for your use. Next slide, please.

The other thing to note is that we are working to think about ableism. There was a recent workshop that I've highlighted here just to make sure that we understand that we know that this is pervasive in research. We know that we've excluded people with disabilities and we need to make sure that they are included and that their lived experience is valued.

Next slide, please.

We also have an open funding opportunity about understanding and mitigating health disparities experienced by people with disabilities focused on ableism, thus welcoming proposals and observational studies as well as system levels intervention studies. This is co-sponsored by my institute, NICHD, the National Eye Institute, and the National Institute of Biomedical Imaging and Bioengineering. This does require plans to include lived experience. Next slide, please.

We're also looking at these accessibility recommendations. We've tracked those and we have accountable entities assigned. We are looking at culture ableism and our research policies and systems, and this includes our training policies and our training programs. Next slide.

I know this work well because I'm one of the co-chairs of it, so I'm going to be working with my colleague, Ellen Rolfes who's an executive officer. She's going to lead a lot of the HR work, and that includes people coming into our intramural science program at NIH and our labs in the clinical center, as well as Kevin Williams, who is our lead for the Office of Equity Diversity Inclusion, is also an EEO attorney. These are great colleagues and have really helped me to scope this work to make sure that we can make really significant change across all aspects of NIH. Next slide, please.

Just to let you know, we know that we need to address the stigma associated, we need to combat discrimination. We need to make sure that people feel comfortable applying for diversity supplements as a person with a disability to disclose their disability status as a researcher, so we know how many researchers are out there with a disability, and really try to move away from the medical model or definitions that stigmatize people with disability. Next slide, please.

We're going to try and figure out how to increase our options and career paths for disabled people in biomedical and behavioral science. We really have a very low rate of people applying to us for diversity supplements as well as investigators with disabilities, so we're going to have to work very hard with the community to see how we can make this better, and also look at our policies and programs for structural change to welcome you all in to write grants and seek support for your science. Next slide, please.

Also, to make sure that our campus and our hybrid meetings are welcoming, so look at our facilities, our design, our accessibility barriers, our materials to make sure they're 508-compliant and consumable, make sure we have low-barrier opportunities to participate in our meetings and benefit from the knowledge we share. Next slide, please.

I think this is an exciting time at NIH. I think we're going to be doing some really good work, but it wouldn't be possible without my colleagues who have really pushed the NIH to make this a priority, so I want to thank them and the community as a whole and I look forward to working with you all as we move this forward.

**Dr. Mia Smith-Bynum:** Thank you so much, Alison. That was a really wonderful and timely overview of all the issues longstanding and late breaking that this field is dealing with. I want to take a moment to go back and acknowledge three of our panelists who are the co-authors of the recent NIH report on scientists with disabilities. I'll come to the lead. I'll re-mention your names again, and then come to one of the co-chairs. Dr. Bonnie Swenor, Dr. Steven Barnett, and Dr. Lisa Iezzoni are the co-authors of this very timely report. Bonnie, if you could talk to our audience about what the impetus for that report was, and then briefly summarize those recommendations?

**Dr. Bonnie Swenor:** Sure. Thank you so much. I am Bonnie Swenor. My visual description is I am a late middle-aged white woman with shoulder-length blonde hair. I am wearing a dark top. I just want to first extend my thanks to Dr. Cernich for that wonderful introduction and for all the work being done in response to our recommendations. Alison did a lot of heavy lifting in describing this effort, so much thanks to Alison. Yes, I was nominated by my co-chairs, Lisa and Steve, to speak first about this effort. Thank you for this question about the impetus, and I think that's an important one to scene set.

Historically, Alison showed some of the data, people with disabilities have been excluded from biomedical research, from training environments, from research studies, and historically that exclusion hasn't been acknowledged or prioritized in efforts to diversify science and research. There's been grassroots efforts to change that, largely from people with disabilities, people like myself and others on our committee to really push for change. I think there was sort of a combination of events that led to this committee being formed.

I think there was more cohesion going on among the community of researchers with disabilities. I also published some data that I obtained via Freedom of Information Act request. Alison referred to it on the proportion of NIH-funded investigators and applicants that report having a disability. That percentage started at 1.9% in 2008, we had data for every year, and declined to 1.2% in 2018.

If you compare that to the prevalence or the percentage of people with disabilities, adults in the United States which is about 26%, 27%, we're not doing so well. I think with the growing advocacy and some data, we got some traction. NIH responded and called this committee to ask a group of 13 of us, the majority of which had disabilities identified as having disabilities to develop recommendations and to work with the community, to work with leadership at the NIH to outline a roadmap of how to do better, and that's what we did. We came out with a set of nine recommendations. Alison outlined some of them. I can go into them in further details, my co-chairs.

We met for over a year in conversation and deliberations with our committee, really sharing our personal stories in the beginning, which were very similar, or about the barriers we faced. From those important conversations really came the themes and issues that we felt needed to be tackled and prioritized, which then informed our recommendations. Reviewing some of the questions that we were given from potential audience members and that have been coming in, these questions are very similar, they're issues of feeling alone, issues of feeling like you don't have a community of people to support you, of mentors that understand you, of environments that include you, of efforts that are trying to make change. I think we all largely felt that and wanted to work together to try and really create that roadmap for everyone.

That really was the impetus for the recommendations, and we were grateful that in December of last year, when we presented these recommendations per procedure to the NIH Advisory Committee to the Director which was our next step in the process, they were unanimously endorsed. After that step was then on to leadership, so our recommendations were endorsed, and now NIH is taking them under consideration and moving them forward as Alison has outlined. Alison really has outlined their NIH taking the baton. Certainly, some bumps in the road we can talk about specifically, but that's the background.

**Dr. Mia Smith-Bynum:** That's really very helpful. As I've been reviewing some of the questions that are coming in from our attendees, and I see a couple of different themes here, some of the questions and comments also have to do with the very issues, Bonnie, that you mentioned, that our programs, our academic training programs don't-- that they're not conceived with a wide array of abilities in mind when we're thinking about admissions, when we think about training, the physical built environment of those settings. I think in one of our other questions that came in ahead of the webinar, hybrid formats that would allow people with different disabilities to actually participate in the scientific enterprise, throughout the pathway from a nascent student thinking about a career in research moving on up through the professional trajectory to becoming a scientist.

Can you are any of the other panelists who are here, talk a little bit about the barriers in terms of access because that's a huge issue as well in terms of-- when I read the report, that was one of the key highlights that I recall seeing as well. Dr. Lisa, your camera came on. You have a burning comment.

**Dr. Lisa Iezzoni:** I feel so badly for Bonnie. We kind of made her take the lead here, so I'm just going to take it over for just a second, then we'll hand it back to you. I do want to underscore our thanks also to the group led by Marie Bernard at the National Institutes for Health. I will confess that when we started, we were all circling each other trying to figure each other out, trying to figure how this was going to work itself out. It worked beautifully. I think that people felt that there was a safe space that we could really reveal our truths about what our experiences were and I cannot thank her and her colleagues enough for welcoming us and listening to us and acting on what they heard. That was just a really good experience.

I am going to for a millisecond reveal that I'm a pre-ADA person. I have had multiple sclerosis for 47 years. I was diagnosed when I started at medical school. When I was at medical school, it was before the Americans with Disabilities Act, and my medical school refused to write a letter for me to go on to train. Although I have an MD degree after my name, I never was able to be a practicing doctor. I'm an example of what you don't want to be. I raised this because we have the ADA that went into effect in 1990. More important also to my story is we have Section 504 which was to protect disability rights in the setting of programs that receive federal funding like a lot of educational programs do.

Neither of these two laws are what's called self-enforcing. There isn't "an ADA police" or a Section 504 Police that goes out there and make sure that every community is accessible, or every setting is accessible. The way the laws are constituted, people have to come forward and say, "I need these accommodations," and negotiate to get those accommodations. This is really, really hard especially when there's a hierarchy within an educational or academic setting. When you're the low person on the totem pole, are you going to feel comfortable coming forward and saying, "Look, I've got a learning disability. I have hearing problems. My legs aren't working as well as they used to." Are you going to feel comfortable doing that?

That is what makes you feel alone because you feel that you are not normal. You're told that there are norms, and you don't fit them. What we are trying to do is eliminate that thinking, just talk about disability as a difference. It's a universal difference that will affect almost everybody across their lifespan and so yes, we can say that 27% of adult Americans now report at least some form of disability, but over the entire lifespan, almost 100% of Americans will do that.

I think that because the law isn't self-enforcing, it's hard for people within a hierarchical system to feel that they can come forward and request accommodations that we do need to think about something called structural ableism, that the structures within which we work and live and play and live our lives are just not set up in so many ways to accommodate the needs of people who live their lives differently.

I think that one of the really excellent things that NIH is doing, hopefully with our recommendation is really stepping back and looking at the structures at all levels, structures including data, including help people get access to the online computerized grant application system. If you can't get access to this very complex system because of let's, just say vision, it's going to be really impossible for you to feel comfortable participating fully as an investigator in NIH. There are so many layers of systems and systems include people, they include policies, they include computers, they include physical settings, et cetera. It's just really exciting seeing the team that has been put together with Alison's leadership to really look at all these different systemic layers.

I do just want to comment on one more thing, and then I will be quiet, and that is that Bonnie and Steve can confirm that I was the person who really pushed, push, push, push to have an appendix to the report that included abstracts of all the NIH and Arc-funded research about disparities for disabilities to show that people with disabilities actually fit the technical definition of a disparities population. Recommending that NIMHD and Arc include people with disabilities as a formal disparities population was actually not within the scope of our initial charge, but we realized we needed to go there. That is part of the recommendations of this report, and we very much hope.

The scientific and advocacy communities really, really hope that this decision that came through about a week ago will be looked at and thought about in the context of that just overwhelming evidence of the disparities that people with disability experience.

**Dr. Mia Smith-Bynum:** Thank you for that, very, very rich comment. Thank you for sharing because I think you've highlighted, Lisa, the burden of people having to disclose personal information when the assumptions that everyone can access whatever they need to complete their training or to execute their day-to-day research responsibilities, that that's a huge burden and that compounds the lived stigma experiences as well. Let's see. I'm taking a look at the chat again and I'm seeing a couple of different places. This issue of training keeps coming up, so I'm just going to read this comment briefly. Kathleen, as one of the co-founders of DARN, if you'd like to also weigh in on this as well.

I'm confused as to what focus and efforts are being made on the ground for graduate student-disabled scientists. The current state of programs are dangerous for disabled students; debt and inefficient student access across programs, zero flexibility to medical issues, atrocious health insurance, not to mention the significant challenges in reaching the extreme high expectations of graduate school applicants. Kathleen, if you could talk about the impetus for founding the Disabilities Action Research Network and talk to our attendees about that and about psych science in particular.

**Dr. Kathleen Bogart:** Sure. Yes. I'm just so thrilled to be on this call with so many of my disabled role models and mentors, so really glad to be here. I'm really glad that APA is hosting this important conversation. To give a background and context about why we founded DARN which stands for Disability Advocacy and Research Network, the context really sounds a lot like what Bonnie was describing and what Lisa was describing. We started from this grassroots place. We are all leaders, all founders, we're disabled, and we are all volunteers in this space. Speaking from my personal experience, I was born with a disability called Moebius syndrome. It's a very visible disability and I have facial paralysis.

Throughout my graduate career, even my undergraduate career, I longed for people who were like me, not necessarily who had my exact same disability, but who identified as part of this larger group that I could feel solidarity with. I longed for role models, psychologists, professors with disabilities who could show me the way and show me there is a place for me in psychology. Unfortunately, I did not have those connections by and large when I was coming up in grad school. I was fortunate enough to start connecting more with people as I began my faculty position, and eventually, we coalesced into forming DARN.

DARN was originally funded by SPSP, which is the social and personality division of APA and now we are broader than that. We hope to include anyone with a disability or who focuses on disability in psychology, including students. What we do is we facilitate community building and networking. We have professional development opportunities, and we share resources. Probably the main way to find out about what we do is to go to our website which is [darndisability.org](http://darndisability.org). We have quarterly virtual meetings where people are able to connect. We have two subgroups and we're growing. One subgroup is focused on the teaching of disability and teaching about teaching while disabled in psychology.

Then the other subgroup is focused on conducting research while disabled and researching disability in psychology. We are beginning a clinical and broader health services group starting in January. Our group is here to help form those grassroots connections so that graduate students not only feel less alone, but they can actually trade notes about what is working for them and they can connect with people who are in positions of power, psychologists who may be able to give them specific advice and advocacy support when they are in this position of relative low power when you're a graduate student.



Some of the points that have already been mentioned are things that we talk about a lot in DARN; the need for flexible work, the need for the ability to work remotely or hybrid. We need to build into our conversations about DEI disability. So often disability is forgotten in that conversation. I think this starts right when we start recruiting students into our programs.

We need to be sure to talk about disability as one of the groups that we support and encourage applications from. When we have our students go through their trainings and orientations about where to find various resources, we need to be very clear and transparent, say the word disability, and talk about the resources and the places that they can go to get support because as was mentioned earlier, disability is a very common experience. You might happen to enter graduate school without a disability and acquire one at some point.

Some of the leaders of DARN acquired disabilities later in life while they were already faculty. This is a minority group that you can either be born into or you can join at any time.

It is really relevant to everyone, and they need to know that there is support and places to go. I think Lisa said it really well when she named structural ableism. There are really high-level things that need to be done to be sure that training spaces are accessible and safe for disabled people. There are also specific things like the programs that we use to analyze our statistical data often are not accessible for people who use screen readers. The gatherings that we have as professionals, conferences were mentioned. Many of those spaces are not fully accessible.

I could go on and on here, but I just want to say that there are a lot of parallels between what started our conversations in DARN and what started the conversation in the NIH group, and that is that we know that people with disabilities are very underrepresented in psychology and in APA. As was said before, we need to do better at measuring disability because it truly is a demographic variable that has a lot of meaning. We can't improve what we don't measure. The small amount of data that we do have suggests that just like 2% of people in APA identify as having a disability. In SPSP, maybe about 5% identify that way.

Again, the data is not good because we're not good at measuring it, and people feel too stigmatized to disclose. Having conversations like this are really crucial to creating a structure and a space that would make it safer for people to disclose and to come up in our field.

**Dr. Mia Smith-Bynum:** Awesome. Thank you so much for that, Kathleen. As I've been scanning the chat, as you and your co-panelists have been speaking, I'm hearing there's some anonymous posts here as well as some where people felt comfortable enough to include their name, where they talk about the extreme isolation and what can be done. Let me just say, as a host of this webinar, one of the reasons why we wanted to pull this together is that when we've hosted several of our webinars on other topics in the past, whether it be graduate admissions or some other topic, a good 10% to 30% of the questions come from attendees who are also identified with this community.

In that respect, we wanted to center this topic so that we could bring more visibility to it. In that way, the products that have been produced by our co-chairs here, the NIH report, if you watch your email after the webinar is done because I think we put all those things in the chat and the chat is now temporarily closed, please go back and pull those links. They are filled with resources and information. There's also a native link to the actual report itself. Anyone who is an administrator of an academic program should be reading that report and looking at ways to implement it on the ground in their institutions because ableism, it's all about the policies, and so we've got to fix the policies.

Then I also see the tremendous burden that our attendees are talking about in terms of educating those in power about those disabilities and the needs that people experience in order to be successful. Dr. Alison, would you like to weigh in on that as a representative of a major policy-making institution? [laughs]

**Dr. Alison Cernich:** I want to say NIH is only one way that we engage the scientific community. We are a very large funder of medical research, but I also want to just give a shout-out to the National Science Foundation as well. They have an incredibly active program that encourages scientific career development for people with disabilities. They are also responsible for some of the largest efforts to track people in sciences with disabilities and recognizing as a psychologist myself. I'm a clinical psychologist, that's what my PhD is in. Psychology is a very broad field. We get funding from a lot of different agencies. I will say the National Science Foundation is probably the broadest in terms of its budget, coverage, and scope, and also funds a lot of our psychology colleagues.

NSF has done an incredible job in engaging the disability community and having opportunities for training and fellowship for people with disability. I will say both from the NSF and the NIH side as well as another organization within HHS, the National Institute on Independent Living, Disability and Rehabilitation Research, we are all working together in many respects to try to look at how do we better include and encourage scientific careers for people with disabilities? That partially has to do, too, with some of the things that you're talking about. How do we make people aware that in their notice of award, there are protections for them?

For example, if someone has guaranteed in your grant application that you have access to certain resources or that you're going to be provided with accessible facilities, if your university violates that, you need to bring that to the attention of the funding organization. We have enforcement capabilities for that. You're violating the notice of award and we can help you and be an advocate along with you.

The other thing is that we are very much about not allowing harassment or discrimination, and that is part of our legal mandate. That is another place where we are pushing internally to make sure that people are aware both of Section 504, but also about the protections that you have within the notice of award to be free from disability, discrimination, or harassment. That is something that comes into our research integrity office and that we take very seriously, just like sexual harassment. I'm a woman in science. I'm not going to say that I've had an easy time of it. I luckily have not had something really untoward happen, but we deal with this the very same way we would with sexual harassment or racial discrimination.

I will also say, I want you to know that you have allies at the NIH. There is a large community of folks that are really, really invested in bringing people with disability into this field, into STEM, same at NSF. The reason for that is, and I have always said this, I think all of my colleagues bring different perspectives, and the perspectives of people with disability are just as valuable as somebody from a minority group or from a sexual gender minority perspective. We bring a lens, and through that lens, we learn a lot about that science. That could be basic science, that could be clinical science, observational studies, qualitative studies. I do think having that diversity makes our science stronger. I just know that you have allies across these agencies that are very much paying attention to this.

**Dr. Mia Smith-Bynum:** Okay. Bonnie.

**Dr. Bonnie Swenor:** Yes, thank you. Thank you, Alison, for elevating the work at NSF, which has been great. I also wanted to chime in about work from the White House, from the Office of Science Technology Policy. I shared in the chat with the backroom team that there was a roadmap released last year on STEM equity that did include a focus on people with disabilities and trying to address the barriers that people face from the White House on down. There's new staff in OSTP focused on these issues, which is fantastic. I also just want to add some reality here that the movement will require continued advocacy. I know Alison is working very hard, but there still are barriers. There's still folks that hang tight to ableist views that make important policy decisions in these agencies and spaces, despite I think the great work of the folks we discussed today and who are on the call.

I guess all this to say is I encourage those on the webinar or allies to continue to advocate for change and to uphold accountability and driving change. Many of the recommendations from our committee have been moving forward, but not all, and some are facing barriers. The fight's not over, but we certainly have had more progress than I ever would have imagined in my lifetime.

**Dr. Mia Smith-Bynum:** Awesome. We have about nine minutes left. I'm going to pose this to any of our guests. One of the things that we know about systematic oppression, and as Bonnie just alluded to that when you're not in the space, ground ends up being seated and so people have to stay vigilant. If there are any comments on two matters, on what allies can do and people who want to be active and to be on the side of a more inclusive workforce. Then for our attendees who are hoping to "be where our panelists are," credentialed scientists who are out there doing good work, whether it be on this topic or others, but who may be living with some type of disability, there are lessons that our panelists may have that can inform this discussion and be encouragement to folks who are listening. I'd ask folks to weigh in on the matter of allyship and also for mentorship, guidance, and encouragement, if you will.

[pause 00:49:28]

**Dr. Mia Smith-Bynum:** So Bonnie and then Alison, please.

**Dr. Bonnie Swenor:** I don't want to--

**Dr. Mia Smith-Bynum:** Please. You've got a couple of lines. Bring it.

**Dr. Bonnie Swenor:** No, I think this is great. It's great to have these conversations about allyship. From my perspective, I think allyship starts with approaching with humility and from understanding that this is a journey and not a destination like we are for many of these spaces, and centering the conversation, the decisions on people from the community. I think that too often, particularly in disability spaces, that doesn't always happen. We're centering these decisions on people that aren't from our community.

Allies work to provide those spaces and bring people in. I've known Alison long enough to know she's a phenomenal ally in this space and does exactly that. Again, starting with learning, and learning history of people with disabilities and disability justice from people with disabilities, but also recognizing it's not our job to necessarily teach that. There's writings, there's scholarship from disabled researchers to start with as a baseline and then start to understand everyone's role. We all, disability or not have a role to play in making change in pretty much every decision we make all day and make an action plan. That's my suggestion.

**Dr. Mia Smith-Bynum:** Thank you for that, and Alison.

**Dr. Alison Cernich:** I think if you are a person who is an ally of the disability community, and I am grateful for Bonnie, I think in all humility, I try every day to be a better ally, I think you have to start with humility. You have to start with full disclosure. I've worked with people with disabilities since the Wayback Machine when I started my career in my undergraduate psychology degree. I think you have to start with the same perspective taking you would take with anybody who is different than you, and really try to think through what you need to know first before you speak on behalf. Then make sure that you are coming from that place and thinking about the needs of the people who you are allied with, and using your power-privilege position to their benefit.

I am in a very I guess some would say probably in a powerful position. My institute works a lot with communities with disability. I have to stop and make sure that what we are doing and the programs we're putting forward best serve that community and not whatever great idea we have, that we're going to have an impact. That's basic science, that's translational science, that's clinical science, that's web resource. Is that accessible to our community, is it understandable to our community, and do they understand why we are doing it and is it going to serve a need for them.

I think if you come at it from that perspective with that alliance with those folks, and also willing to stop, and if you've not done it the right way and the community gives you that feedback, to stop and listen, and to really try to understand what barriers you're putting in place. I think you can get there a lot farther and a lot faster by listening and taking that feedback in. You may not be able to do all of it, but I think we can learn a lot by listening. I think psychologists know that inherently, but I don't know that we always take it to heart and do it when we're running big programs and policies.

**Dr. Mia Smith-Bynum:** Thank you for that. We have about four minutes left. Let me just acknowledge one comment that when staff at APA and I were working to put this together from an attendee by the name of Max Taylor who talks about harmful experiences he's had with psychotherapy and with various forms of medical treatment and know that the absence of I guess community advocates on the panel. I just wanted to note that we hear that feedback. Regrettably, everything can't be addressed in an hour, so we centered on the experiences of scientists and future scientists with disability. I just want to put that out there. We could spend a day if we had the time in this conversation, but I hear the need to be heard. Now, a little earlier I saw that Kathleen Bogart's camera came on and then Lisa Iezzoni. I want to go back to Kathleen if Kathleen had a comment.

**Dr. Kathleen Bogart:** My comment was, coming to your earlier question, Mia, about recommendations for people who want to go into the field, people with disabilities like me, my recommendation is really to connect with your community. One example that I will give is that, in my own experience, I grew up like most people in a very medical model framework, that is thinking about my condition as just that. My condition, Moebius syndrome happens to be very rare, 2 to 20 per million people, and I thought I would never be able to encounter people who experienced the same thing I did.

Then I started to learn about the social model of disability and how so many of the challenges and stigma and structural things that we're experiencing are constructed societally. They don't depend on a specific diagnosis. As I started to learn that, I started to find community and solidarity with people who had very different medical or disability conditions as me. I just want to remind people out there that you can find community with people who may have very different disabilities than you, that we all have some of the same challenges in common. Challenges that we've been talking about through this entire panel.

I would also encourage the people in power who are listening to remember that, to think about disability as this large, primarily socially constructed group, and that if we get too in the weeds about looking for specific diagnoses or specific medical documentation to give a student or an employee accommodations, we can lose the larger piece here that people with disabilities are a health disparity group that needs support from our systems at large. Think broadly about disability if you're a disabled person or if you are a person hoping to be an ally.

**Dr. Mia Smith-Bynum:** Thank you so much for that, Kathleen. I see lots of comments in the chat where people are trying to find mentors. For our folks who are affiliated with the psychology professional community, please join DARN. It's a great resource. That's how I learned about the new NIH report, is that as folks who are affiliated with APA join, there is a great synergy happening. I want to encourage you to pay attention and stay involved and "watch this space." This has been an Essential Science Conversation by APA. I want to thank all of our distinguished, passionate, and committed guests for coming and sharing your insights with us. Share the report and read it widely. Thank you so much, everyone, and have a great day.