

# Focus on Eye Health National Summit



## A Lifetime of Vision

July 17, 2019 | National Press Club | Washington D.C.



***Afternoon introduction:***



## **Losing Vision and Gaining Perspective**

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 **Prevent  
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**Focus on Eye Health**  
National Summit

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# Losing Vision and Gaining Perspective

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Johns Hopkins University Center on Aging and Health**





A PIECE OF MY  
MIND

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## Losing Vision and Gaining Perspective

**"Lead with your science,** not your disability." Hearing this from a colleague left me stunned. While well intentioned, this advice reflects disability stigma and the common belief that disability makes individuals unable, instead of differently abled.

I was diagnosed with a degenerative retinal disease when I was 26 years old. My initial vision loss was unexpected and life changing. I began to have retinal hemorrhages just weeks after submitting applications to master of public health (MPH) programs. As permanency of my vision impairment sank in, I became convinced that my research career was over before it even began. The timing seemed impossibly cruel. I couldn't imagine or visualize pursuing a research career as a person with a disability, as I didn't know another researcher who had paved this path.

After a period of depression and a yearlong deferment, I challenged myself to make it through just 1 term of graduate school. Fearful that other students and faculty would consider me less competent or incapable due to my visual impairment, I hid my disability. I pretended to see things that I could not in an effort to avoid conversations about my vision. This also meant that I didn't ask for accommodations, missed important

prised, "If you can't talk about your disability then, how can I?" I was speechless. The patient was right. This tough conversation forced me to challenge my own behavior and question how I could be both afraid to reveal my disability status yet dedicate my career to helping others like me. I think about this patient often, especially when I feel defeated, vulnerable, or stigmatized, and it reminds me of my valuable dual role as a patient and researcher.

I briefly believed that outing myself as a person with a disability was enough, but quickly realized that the barriers for faculty members with disabilities surpass personal acceptance. As an academic researcher, I am responsible for developing my own research ideas and obtaining funding for myself, staff, and collaborators to achieve these goals. Productivity is crucial. Promotion, invited talks, and committee membership hinge on your colleagues' judgment of your abilities. Although all academics are chasing these goals, scientific success is often more difficult for persons with disabilities. We must not only work to meet the sensory, physical, mental, or emotional needs that come with being differently abled, but also combat the stigma associated with d

JAMA®

# Disability Inclusion — Moving Beyond Mission Statements

Bonnielin Swenor, Ph.D., M.P.H., and Lisa M. Meeks, Ph.D.

Dr. L. graduated summa cum laude from an Ivy League medical school, but her dream of becoming a physician-scientist was challenged when, after she was involved in an automobile accident that resulted in a traumatic brain injury, the chair of her department expressed doubt that a “disabled physician” could practice medicine. Dr. L. was devastated. She was fatigued, and staring at computers to do her charting exacerbated her newly developed migraines. She asked for accommodations including dictation software that would reduce the amount of time she spent looking at a computer screen and an adjusted work schedule to permit 8 hours of sleep per night, which reduced her migraines and

the costs of the software (\$2 and of covering her clinical overnight. Dr. L. was forced to leave academic medicine in of a small private practice where she could better regulate her schedule.

Over the past decade, research institutions have embraced the importance of diversity and inclusion in the biomedical workforce in response to concerns about the underrepresentation of certain groups, including women and racial and ethnic minorities. Yet people with all categories of disability remain absent from going efforts to enhance the workforce diversity. A recent Association of American Medical Colleges (AAMC) report addressed strategies for removing barriers

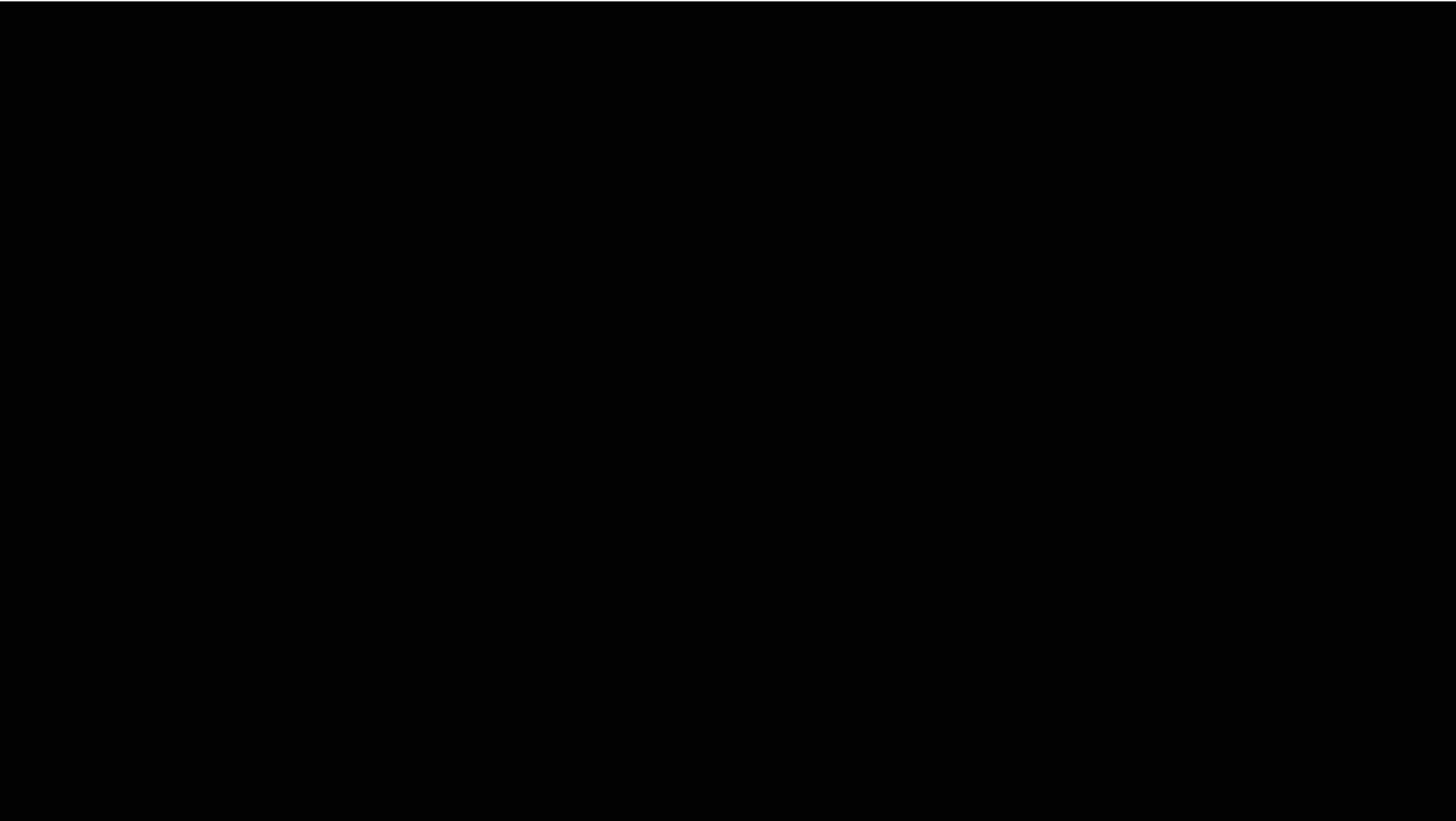
Table 1. Best Practices for Building an Inclusive Environment for People with Disabilities in the Biomedical Workforce.\*

Best Practices	Approaches to Implementation
Make disability part of broader diversity efforts	Integrate disability into diversity initiatives, efforts, and language; meaningfully integrate disability into diversity training
Educate community about faculty members with disabilities	Provide educational experiences and conduct campaigns that highlight the work of physicians, scientists, and faculty with disabilities, ensuring department chairs, program directors, and leaders understand the commitment to disability and the appropriate referrals for applicants with disability-related questions
Send a clear message about inclusion	Post statements about the inclusion of people with disabilities and links to the appropriate office for disclosing disability status and requesting accommodations on department websites
Seek to hire qualified faculty members with disabilities	In postings for faculty or postdoctoral positions, make clear statements about the institutions' desire to hire people with disabilities
Invite speakers with disabilities	Ensure that talks, seminars, grand rounds, and faculty training include opportunities to engage faculty with disabilities focusing on their science, in addition to general diversity and disability content
Maintain a neutral-party disclosure system	Have a clear process for requesting accommodations that does not involve direct disclosure of disability status to a colleague or supervisor
Maintain a confidential and informed interactive process	Employ someone with knowledge of disability, disability-rights law, and accommodations in a biomedical setting as the point person for confidential disclosure of disability status and to lead the interactive process of determining accommodations
Centralize accommodation expenses	Develop and disseminate a clear understanding of the financial obligation to provide accommodations and ensure that accommodations are adequately funded
Measure growth	Count people with disabilities in diversity assessments using anonymous self-reporting, identify trends in the number of faculty members with disabilities, and use these metrics as an indication of the success of inclusion efforts
Invest in training and career development	Invest in the training and career advancement of scientists and physicians with disabilities
Engage the disability community	Engage representatives from the disability community to understand what is needed to help people with disabilities be successful in their careers
Support leadership development	Place faculty members with disabilities in leadership roles where they can positively influence decisions and policymaking



The NEW ENGLAND  
JOURNAL of MEDICINE

Of employed scientists  
more reported having a  
more than half (55.7%)







I have gained  
more  
than I have lost





THANK YOU

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