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<https://www.captionedtext.com/client/event.aspx?EventID=3793506&Customer...>

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For questions about the presentation, there will be a Q&A session at the conclusion of the webinar. The operator will provide instructions on how to submit questions.



# Medical Professionals with Disabilities Webinar

National Disability Employment Awareness Month  
October 24, 2018



# Webinar Agenda

## I. Introduction

## II. Presentations:

- Michael McKee, *MD, MPH, University of Michigan*
- Lisa I. Iezzoni, *MD, MSc, Harvard Medical School*
- Karen McCulloh, *RN, Co-founder and Director, National Organization of Nurses with Disabilities*
- Neera Jain, *MS, CRC, PhD Candidate, University of Auckland*

## III. Question and Answer Session

# Disability is Part of the Diversity Equation- A Deaf and Hard of Hearing Update

Michael McKee, MD, MPH



# Underrepresentation in Health Care

*Despite the passage of the Americans with Disabilities Act over 25 years ago, only 1% of medical students and 2% of practicing physicians reported a disability*

McKee M, Case B, Fausone M, Zazove P, Ouellette A, Fetters M. Medical schools' willingness to accommodate medical students with sensory and physical disabilities: ethical foundations of a functional challenge to "organic" technical standards. *AMA Journal of Ethics*. 2016;18(10):993-1002.

<http://journalofethics.ama-assn.org/2016/10/medu1-1610.html>



# Diversity Includes Us!

Inclusion of DHH in health care and research benefits everyone

- Improve care and access for patients with disabilities
- Improved understanding and empathy
- Introduction of new strategies for engaging and caring for patients
  - Breaking down barriers to health care
  - Development of novel curricula and opportunities

McKee M, Case B, Fausone M, Zazove P, Ouellette A, Fetters M. Medical schools' willingness to accommodate medical students with sensory and physical disabilities: ethical foundations of a functional challenge to "organic" technical standards. *AMA Journal of Ethics*. 2016;18(10):993-1002.



# Stethoscope Evolution



# Technology Advancements

- Universal designs
  - Light based alarms for health care
  - Voice to text systems
  - Surgical masks
- Remote CART service
- Video remote interpreting

## Deaf Professor Brings Transparent Surgical Mask to US Healthcare to Facilitate Lipreading and Communication



Anne McIntosh didn't plan to become an entrepreneur, but when she delivered her baby, her world changed. When she needed an emergency c-section, everyone donned masks. Hard of hearing, she lost her ability to communicate when she could no longer read lips. She's spent 16 years bringing a transparent surgical mask to market. Interview with ... [Continue reading](#)



# Advocacy

**AMA Journal of Ethics®**

October 2016, Volume 18, Number 10: 993-1002

## MEDICAL EDUCATION

### Medical Schools' Willingness to Accommodate Medical Students with Physical Disabilities: Ethical Foundations of a Functional Challenge to "Organic" Technical Standards

Michael McKee, MD, MPH, Ben Case, Maureen Fausone, Philip Zazul, Alicia Ouellette, JD, and Michael D. Fetters, MD, MPH, MA

#### Abstract

Students with sensory and physical disabilities are underrepresented in medical schools despite the availability of assistive technologies and accommodations. Unfortunately, many medical schools have adopted restrictive "organic" technical standards based on deficits rather than the ability to do the work. Compelling ethical considerations of justice and beneficence should prompt change. Medical schools should instead embrace "functional" technical standards, accommodations for disabilities and up-to-date data to promote applications from qualified students. Medical schools thus should focus on what students can do, rather than what they cannot do, because diversifying the health care profession and expanding the population of patients with c

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*AMA Journal of Ethics*. October 2016, Volume 18, Number 10: 1050-1059.  
doi: 10.1001/journalofethics.2016.18.10.sect1-1610.

SECOND THOUGHTS



### Technical Standards and Deaf and Hard of Hearing Medical School Applicants and Students: Interrogating Sensory Capacity and Practice Capacity

Michael Argenyi, MD

## BREAKING: Deaf Nurse Wins Court Case

/ JANUARY 21, 2016 / NEWS, NURSE / 33 COMMENTS

by Michael Argenyi, MSW Lauren Searls is a deaf registered nurse (RN), who has used American Sign Language (ASL) interpreters during her nursing education and works at Rochester Strong Memorial ...

# Pipeline Programs



## Rochester Bridges to the Doctorate

NATIONAL TECHNICAL INSTITUTE FOR THE DEAF | UNIVERSITY OF ROCHESTER  
ROCHESTER INSTITUTE OF TECHNOLOGY

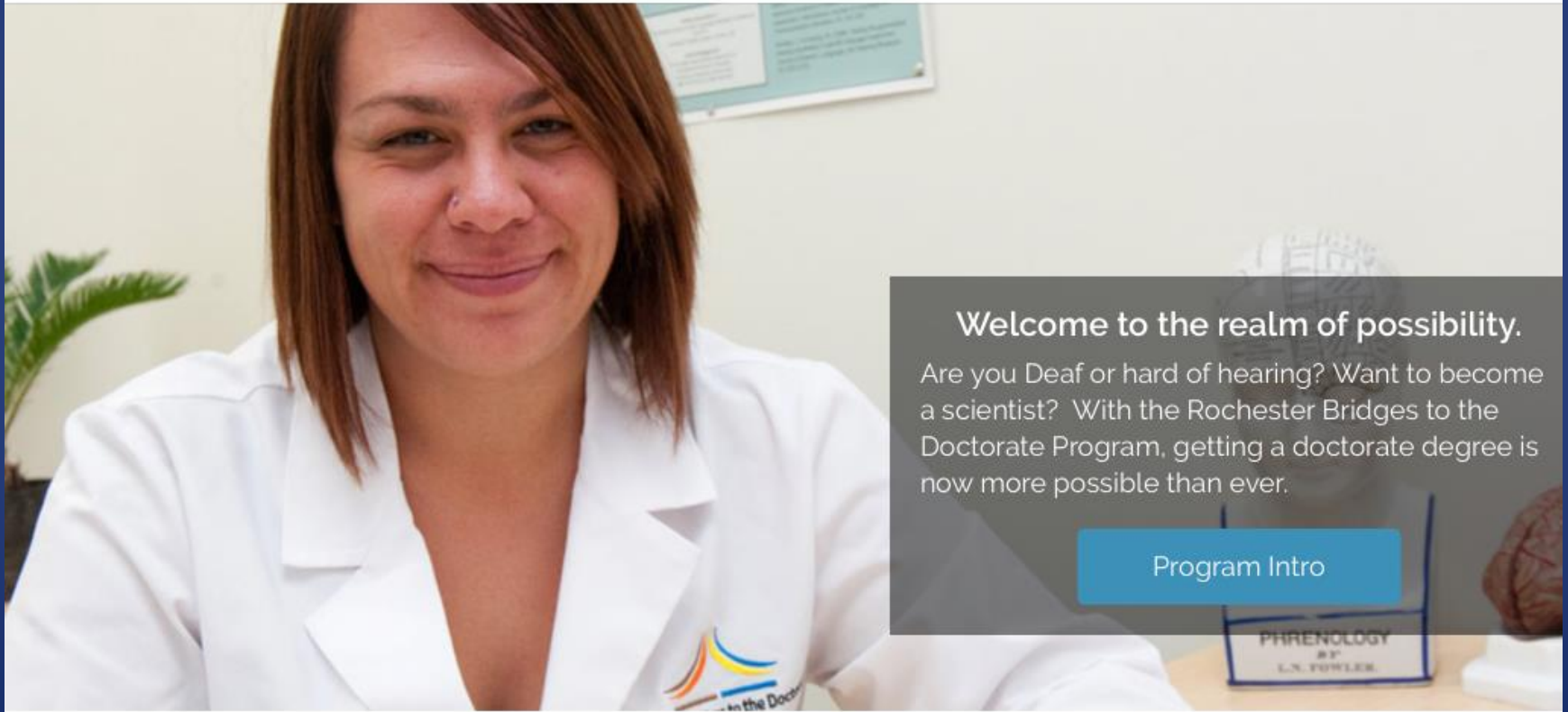
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**Welcome to the realm of possibility.**

Are you Deaf or hard of hearing? Want to become a scientist? With the Rochester Bridges to the Doctorate Program, getting a doctorate degree is now more possible than ever.

[Program Intro](#)

# Association of Medical Professionals with Hearing Losses

A photograph of the Baltimore skyline at night, with various skyscrapers illuminated against a dark purple and blue twilight sky. The lights from the buildings and streets are reflected in the water in the foreground.

# BALTIMORE

AMPHL/ADARA Joint Conference

June 1-4, 2019

[CLICK HERE TO GO THE OFFICIAL CONFERENCE WEBSITE](#)

[www.amphl.org](http://www.amphl.org)

# Contact

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- Twitter: Mike McKee @deafmd1
- <https://medicine.umich.edu/dept/family-medicine/michael-m-mckee-md-mph>

# Medical Professionals with Disabilities: Brief Comments



Lisa I. Iezzoni, MD, MSc

Mongan Institute Health Policy Center, Massachusetts General Hospital

Harvard Medical School

October 24, 2018









1980 - 1984





# Healthy People 2010

## Volume I

- Understanding and Improving Health
- Objectives for Improving Health  
(Part A: Focus Areas 1-14)

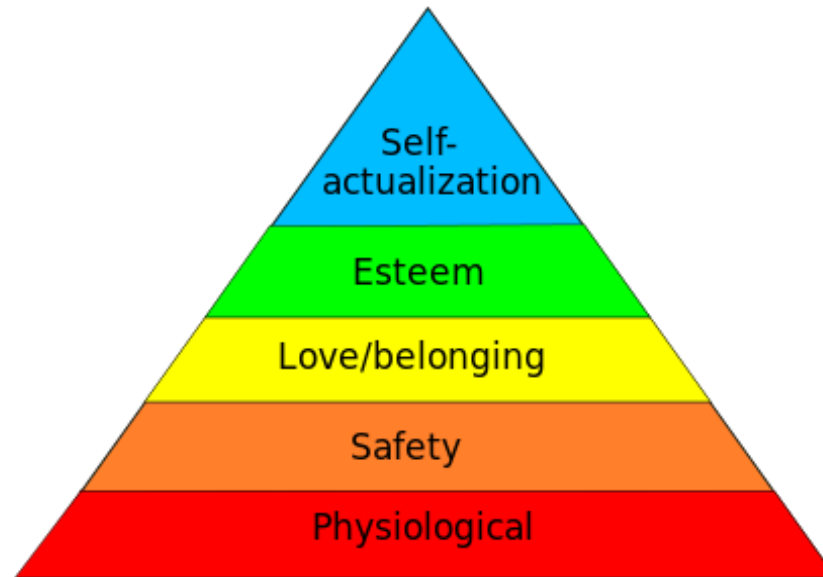


# Healthy People 2020

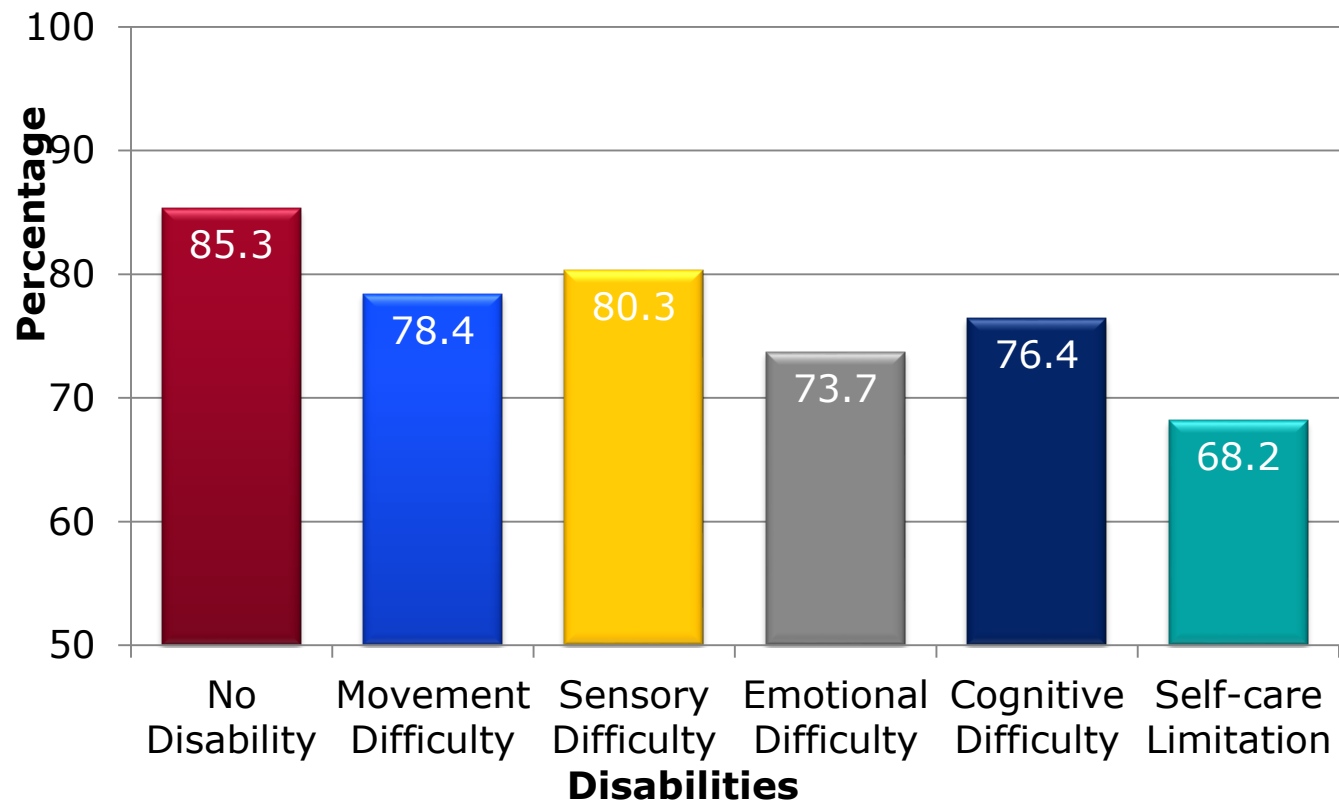


[www.healthypeople.gov](http://www.healthypeople.gov)

# MASLOW'S HIERARCHY OF NEEDS

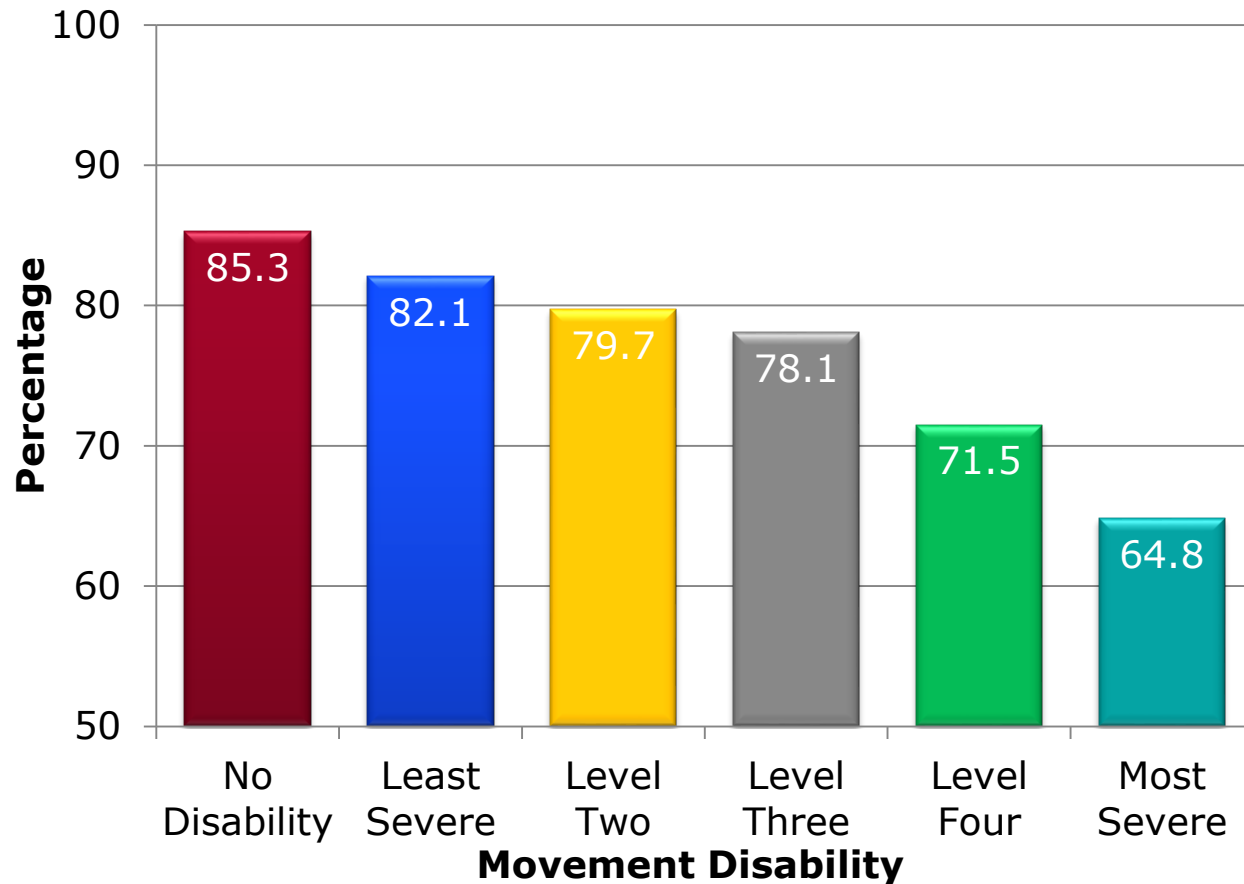


# PAP TEST RATES

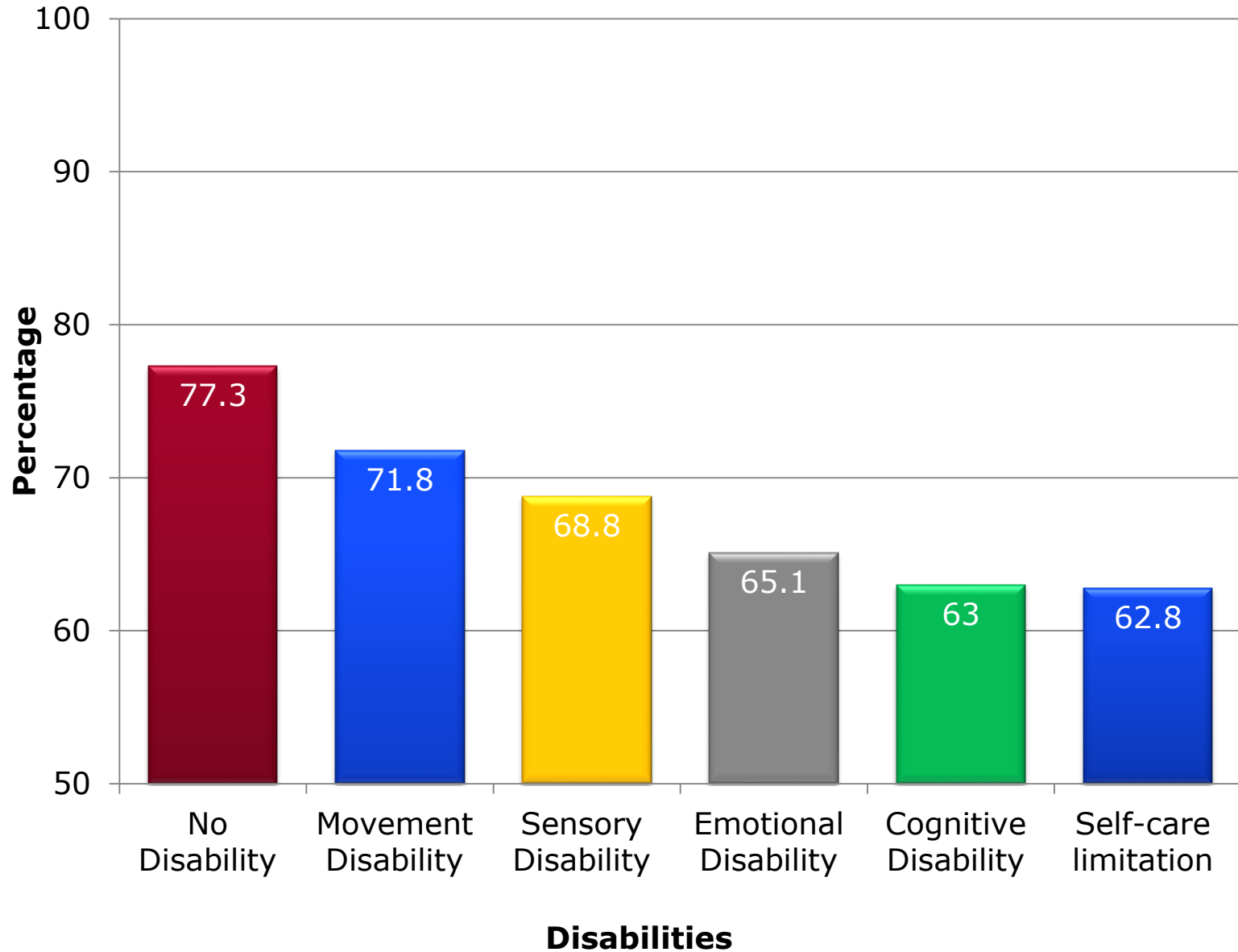


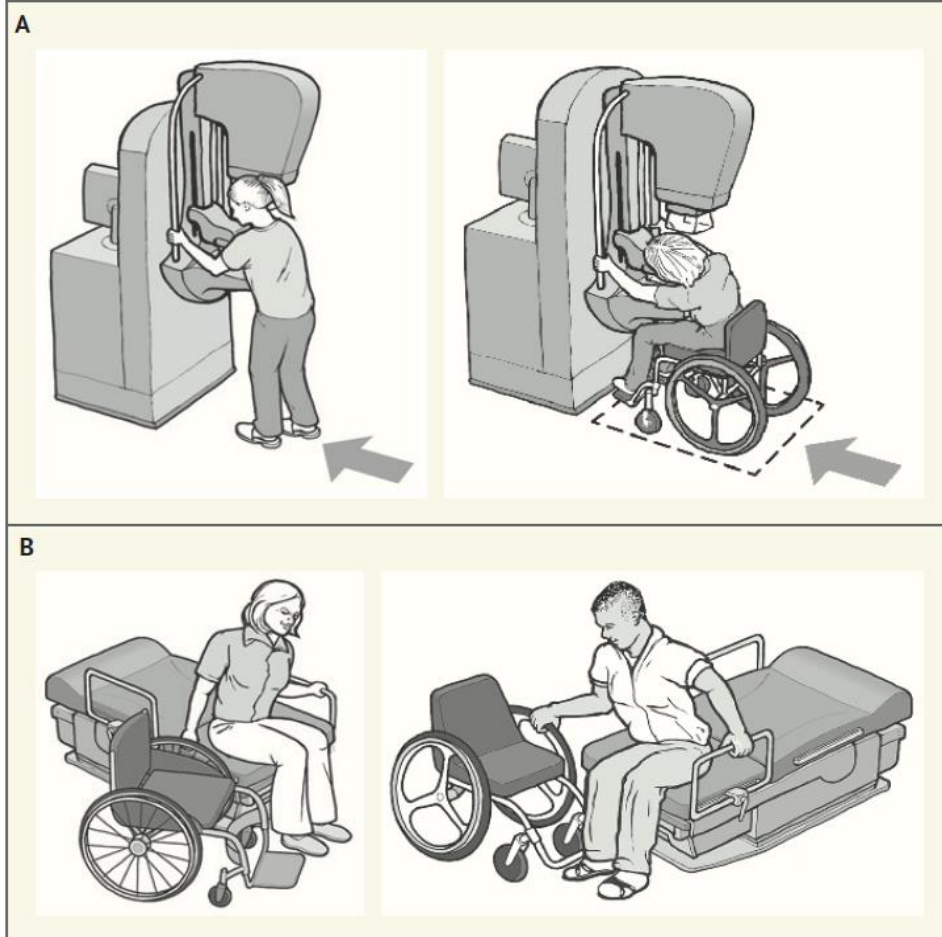


# PAP TEST RATES: MOVEMENT DISABILITY



# MAMMOGRAM RATES





## BREAST CANCER aHRs

Stage	Cancer-specific	All cause
Overall	1.29*	1.98*
I	1.45*	2.84*
II	1.19	2.02*
III	1.12*	1.39*
IV	1.74*	1.68*

\*aHR > 1, women with disabilities significantly higher death rate.  
All women age < 65 years, disability defined by SSDI eligibility.

**“They masking taped my arm  
to the table every day.”**

Sue, cerebral palsy







***The Voice of Disability in Nursing***

**Celebrating Our 15<sup>th</sup> Anniversary Year!**

**Founded in State of Illinois in 2003 as a 501(c)3 nonprofit  
& headquartered in Chicago**

**Presenter**

**Karen J. McCulloh, RN, BS**

**Co-Founder – President-Director**

## Mission

**NOND is an open membership, cross-disability professional organization that works to promote EQUITY for people with disabilities and chronic health conditions in nursing through education and advocacy.**

## Facts About NOND

- **Volunteer Directors assume the leadership, operational and programmatic responsibilities for the organization without compensation.**
- **60% of the Board of Directors must be people with disabilities where the majorities are nurses with disabilities.**
- **Directors are employed in other positions as Nurse Educators,, Researchers, work in clinical areas such as Operating Room, Telemetry, Palliative Care, lead other nonprofit organizations, Case Manager, small business owners, are writers as well as work in the social service sector, and are geographically dispersed across the US.**
- **Directors who are disabled believe disclosing their disability or chronic health condition publicly provides education on “What is Possible!” by nurses with disabilities.**

## SERVICES

- **NOND's Core Services began in 2004: Contacted by parents, high school students, nursing students and nurses with disabilities, other allied healthcare professionals and workers with disabilities for 14 years, and where a great deal of data has been collected.**
- **NOND provides resources, I&R, support and encouragement and mentoring for some individuals. Directors with same or similar chronic health condition or disability provide mentoring as requested or initiated by NOND, and as possible. NOND conducts presentations, publishes articles, and is an advocate opposing policy that may have a negative impact on people with disabilities.**
- **NOND does not provide legal advice but provides legal resources and information.**
- **Emphasis is on SELF-ADVOCACY AND SELF-DETERMINATION!**

# **NURSES ARE HEALTHCARE PROFESSIONALS**

## **OPPORTUNITIES**

### **American Nurses Association (ANA)**

(<https://www.nursingworld.org/practice-policy/workforce/>)

- **4 million RNs (not all are in the workforce.)** CareerOneStop, <https://www.careeronestop.org/>
- **ANA estimates that 500,000 nurses will retire by 2022.**
- **11 to 15 % growth in opportunities.**
- **1.1 million new RNs needed to replace RN retirees & build capacity to address nursing shortage.** (US Dept. of Labor Bureau of Labor Statistics.)

### **Employment Requires Education First**

- **Nursing is a STEM Career---Science—Technology-Engineering-Mathematics.**
- **Students must be academically qualified and meet prerequisites to apply to nursing programs.**
- **In comparison to 2003 when NOND was founded, there are more students with disabilities entering nursing, and most ARE successful.**

## CHALLENGES in EDUCATION

- **Some universities and colleges are less proficient in providing reasonable accommodations while some schools provide accommodations in the classroom but not in the clinical setting.**
- **Technical Standards focusing on functional abilities continues to be a barrier that can exclude academically qualified students with disabilities from some schools. That is you have to hear, see, bend, walk, talk, touch, smell, etc.**

### **To Address Technical Standards:**

**White Paper on Inclusion of Students with Disabilities in Nursing Educational Programs for the California Committee on Employment of People with Disabilities,**

**(2015), Drs. Beth Marks and Sarah Ailey include a model for technical standards for the 21<sup>st</sup> century. The White paper is available on American Association of Colleges of Nursing website,**

**<https://www.aacnursing.org/>**



# **NURSING ACROSS THE LIFESPAN DISCLOSURE**

## **Nurses with Disabilities in the Workforce What NOND Has Learned & Recent Study**

### **Nurses who have contacted NOND:**

- **Non-apparent/ invisible disability-do not usually disclose to employer.**
- **Self-accommodate for themselves—do not disclose to employer.**
- **Disclose to employer, provides documentation - receive accommodations.**
- **Disclose, provide documentation - does not always receive or may wait for extensive periods of time for accommodations.**
- **Some Nurses on FMLA , job no longer exists (downsized ) once ready to return to work.**
- **Nurses terminated or forced to retire based on their employer feedback.**

**Study: Nurses with Disabilities in the Workforce, (2017)  
Dr. Dawn Dubsky, (unpublished dissertation)  
Interviews with 21 nurses with disabilities.**

1. **Self Accommodation: *Nurses feared that requesting accommodation from employers would threaten their chance of being hired or staying employed.***
2. **Inevitable to request accommodation. Chronic health condition or disability may worsen and nurses want to ensure patient safety.**
3. **Self-advocacy: *Participants consistently reported “self-advocacy” (advocating for oneself) was important in the process of accommodation.***
4. **Lack of process. Employer offered “no process” in the workplace that described how to request accommodation.**
5. **Employer Resistance to accommodation: ..... *employers were more concerned about cost of accommodation, patient safety, and the nurses’ ability to do the essential functions of the job.***
6. **Nurses Settled for less.**
7. **Disability identity. *Nurses with disabilities had varying perceptions of how they identified with disability, and this impacted the process of accommodation.***

## POSITIVE CHANGES IN EDUCATION & CONTINUED CHALLENGES

- **Disability Services Professionals' education has improved dramatically since 2003, providing heightened quality of accommodations where more Student Access Offices have been established and located on more campuses, particularly at health sciences universities and colleges.**
- **Many schools of nursing have revised or are revising their Technical Standards to be more inclusive of students with disabilities but challenges still exist in  
Exclusion at some schools.**
- **More students with disabilities are becoming academically prepared but many secondary school age students with disabilities do not know they can be nurses.**
- **More institutions of higher education understand responsibilities to provide for accommodations requests because of the Rehabilitation Act, Section 504 and the Americans with Disabilities Act, 1990 & Americans with Disabilities Act Amendments Act, 2008.**

## CURRENT STATUS

- **Negative attitudes, stereotypes and myths continue to exist-- directed to students and nurses with chronic health conditions and disability in both school and at the workplace but NOND has seen some improvement.**
- **Employer concerns are directed to Patient Safety, Cost of Accommodations and nurses with disabilities meeting the Essential Functions of the Job. No data is available that validates nurses with disabilities practice less safely than their non-disabled peers.**
- **Employer accountability on provision of accommodations needs to be established.**
- **More Diversity and Inclusion initiatives are needed at health care institutions and other health industries. While not a formal requirement, The US Dept. of Labor Office of Finance Contract Compliance 503 Rules set a goal of 7% representation of people with disabilities in the workforce of institutions that receive federal contracts.**

## **NURSES WITH DISABILITIES TRANSFORMAING THE PRACTICE OF NURSING**

- **Clinical tasks no longer have to be performed using the exact same procedures; students and nurses with disabilities may be performing tasks differently but are able to maintain the integrity of the tasks, and where the outcomes are the same.**
- **Advancements in technologies, adaptive devices, Smartphone apps and other equipment provides the opportunity for students and nurses with disabilities to be at a level playing field with non-disabled peers.**
- **Accommodations provided are not “special privileges” but necessary to meet the needs of individuals with disabilities to assist in their success in school and at the workplace, and where they have equal opportunity to choose nursing as their career.**



**TRANSFORMATOIN**  
**Students & Nurses with Disabilities**  
**NOND Believes**

**Students and Nurses with Disabilities are:**

- **Providing Culturally Relevant Care.**
- **Enhancing Communication.**
- **Increasing patient/ consumer involvement with greater self-determination directed to self-care, increased motivation, emphasis on wellness, and independence.**
- **Assisting in the Development of Creative Strategies for long term patient personal goals; acting as role model healthcare professionals with disabilities.**
- **Advancing health outcomes.**
- **Improving Patient/ Consumer Satisfaction.**

**THANK YOU!**

**National Organization of Nurses with Disabilities**

There is a very strong bond between and among nurses with disabilities and those that support us. We have experienced challenges, barriers and for some discrimination. The members of the NOND Board of Directors are passionate about the Mission. We do not want students and nurses with disabilities to experience many of the challenges NOND Directors have.

**Our Work Continues!**

**NOND Board of Directors**

# **Accessibility and Inclusion in Medical Education**

**NEERA R. JAIN, MS, CRC**

**Doctoral Candidate, University of Auckland, Faculty of Education and Social Work  
Board Member at Large, Coalition for Disability Access in Health Science and Medical  
Education**

**Co-Author, Accessibility, Inclusion and Action in Medical Education (AAMC, 2018)**

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“

If you're not perseverant, you suffer.... If you're not ridiculously persistent and dogged and determined to be heard or listened to, you have no hope at all. If you are not willing to find your way yourself, you won't make it. Such high standards are not required of students without disabilities, and that's not fair.

— Medical Student (Meeks & Jain, 2018)

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# PREVALENCE IN MEDICAL EDUCATION

AD/HD **33.7%**

Learning **21.5%**

Psychological **20%**

Chronic Health **13.1%**

Visual **3%**

Mobility **2.5%**

Deaf or hard of hearing **2.2%**

Other functional **3.9%**

**Overall 2.7% (0-12%)** (Meeks & Herzer, 2016)

# THE LIVED EXPERIENCE PROJECT

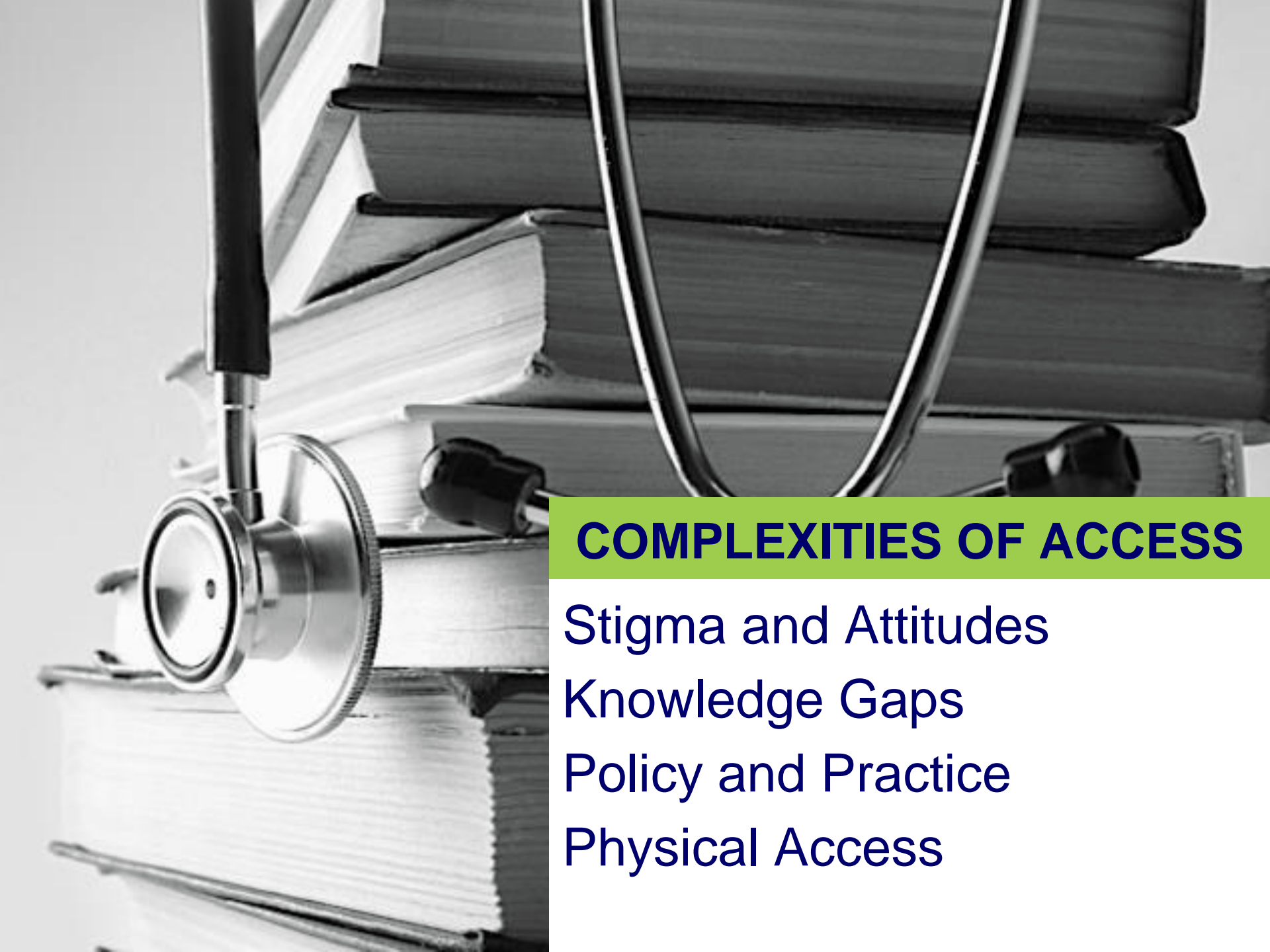
What are the **lived experiences** of learners and physicians with disabilities through training?

Structure // Culture & Climate

- Barriers
- Supports
- Promising Practices
- Considerations

<http://aamc.org/disabilities-report>





## **COMPLEXITIES OF ACCESS**

Stigma and Attitudes

Knowledge Gaps

Policy and Practice

Physical Access



# WHERE TO FROM HERE?

- **Representation:**  
#DocsWithDisabilities
- **Community of Practice:**  
Coalition for Disability Access  
in Health Science and Medical  
Education  
<https://www.hsmcoalition.org>
- **A Roadmap to Reform:**  
<http://aamc.org/disabilities-report>
- **Universal Design Principles:**  
A culture of access?



"As a deaf person in a hearing world, I have often felt vulnerable. I actively encourage my trainees to reflect on times when they too felt vulnerable. This helps them acknowledge the fear and isolation that patients often experience, and promotes their development as caring, empathetic physicians."

MOLLY LUBIN, MD

Assistant Clinical Professor of Psychiatry at  
the University of Wisconsin-Madison  
Twitter: @Mollubin

Submit your story:  
[bit.ly/docswithdisabilitiessubmit](http://bit.ly/docswithdisabilitiessubmit)

**#DocsWithDisabilities**

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“

He said, ‘I think you are going to do something impactful. We want to have you here. If that doesn’t look like what it looks like for other students, that’s fine.’

I really felt settled with where I was with that school after that conversation.

- Medical Student (Meeks & Jain, 2018)

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# References and Resources

Coalition for Disability Access in Health Science and Medical Education <http://hsmcoalition.org>

Meeks, L. M., & Herzer, K. R. (2016). Prevalence of Self-disclosed Disability Among Medical Students in US Allopathic Medical Schools. *Jama*, 316(21), 2271–2272.

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# Q&A SESSION