U Duke University School of Medicine

## "Who's in the Room?"

### Bioethical Reflections on Disability in Health Professions Education

Sarah Jean Barton, ThD, MS, OTR/L, BCP Oregon Bioethics and Humanities Colloquium February 17, 2022







**Occupational Therapy Doctorate** 



# Disclosures

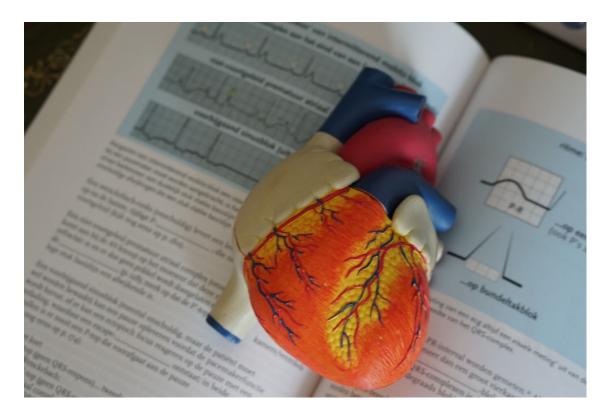
- No financial disclosures
- Member of <u>Access in Medicine</u> working group
- Lived experience
- Duke Medical Center IRB Protocol 00107590



# **Close your eyes and imagine...**



# **Current Literature**



Epstein et al. (2020) "Ask Me What I Need" Meeks et al. (2019) "Change in Prevalence of Disabilities and Accommodation Practices"

# **Current Literature**

# Accommodations, disability and diversity policies, and application of the ADA in health professions education

Argenyi, 2016; Ashcroft et al., 2008; Azzopardi, et al. 2012; Bagenstos, 2016; Baxter et al., 2020; Betz, et al. 2012; Burke, 2019; Davidson, et al. 2016; Dupler et al., 2012; Hori and Meeks 2017; Ferguson et al., 2009; Griffiths, et al., 2010; Hargreaves and Walker, 2014; Hargreaves, et al., 2014; Hoepner and Maheady, 2013; Hosterman, et al, 2010; Howlin et al., 2014; Kezar et al., 2019; May 2014; Marks and McCulloh, 2016; McKee et al., 2016; Meeks, 2019; Meeks et al., 2015; Meeks et al., 2018a, Meeks et al., 2018b; Meeks and Jain, 2017; Murphy and Brennan, 1998; Neal-Boylan and Smith, 2016; Neal-Boylan, et al. 2018; Papanastasiou, et al., 2017; Sharby and Roush, 2008; Swenor and Meeks, 2019; Tee, et al. 2009; Tee and Cowen, 2012

# **Current Literature**

### Faculty perceptions, knowledge, and attitudes

Aaberg, 2012; Ashcroft et al., 2008; Dallas and Sprong, 2015; Evans 2013; Lensmire 2010; Levey 2014; May 2014; Shpigelman et al. (2016); Swenson, et al. 1991; von Bergmann et al. 2017

### **Perspectives from learners**

Bulk et al., 2019; Epstein et al., 2020; Evans 2014; Evans 2015; Hill and Roger, 2016; McPheat 2014; Stergiopoulos, et al., 2018

# "Who's actually in the room?"



"From the onset of our program we need to address the fact that there can be people in the room who have these issues going on. I would see it in my classmates who weren't as sensitive, talking about people with impairments, who deal with chronic pain, who deal with chronic fatigue, as we were learning about them. We need to make it clear that these people are also in the room."

– Hillary (DPT Program)



"A challenge of medical education is that it's always so patient focused, in the sense that it escapes reality that someone in the room might have one of these mental health diagnoses or illnesses or conditions or disabilities that we're talking about. And, that's not true. That can't statistically be true."

– Joy (MD Program)

"I just wish our instructors knew how bad it feels to have to self-accommodate. To be like the one person...like I'm probably really not the only person in the room thinking that, but just how bad it feels...that I can't really pay attention because I'm having to plan my accommodations...It's so obvious, there are plenty of people, including people having a much harder time than me, in the room and everyone's pretending like it doesn't happen. I just wish it was something more openly talked about."

– Opal (MD Program)

"I remember getting the email that you're doing this and being like 'wow, I can't believe somebody is studying this.' Like it's so important. It's so important especially in health professions because how can you expect people to be clinicians and at the same time imagine that everyone who's in the room learning to be a clinician does not have any disabilities, medical problems, or conditions. Like, it's so weird."

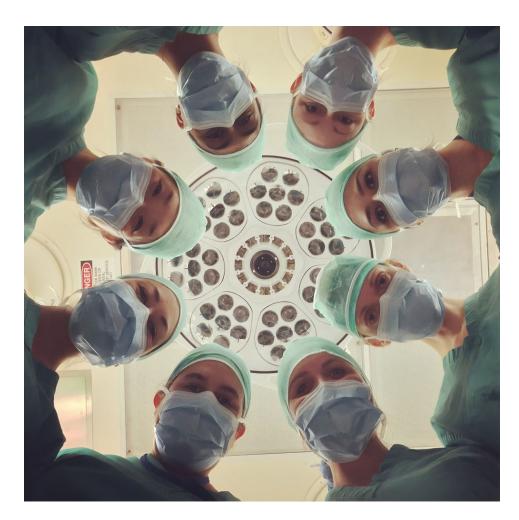
– Opal (MD Program)

# "Who's *imagined* in the room?"





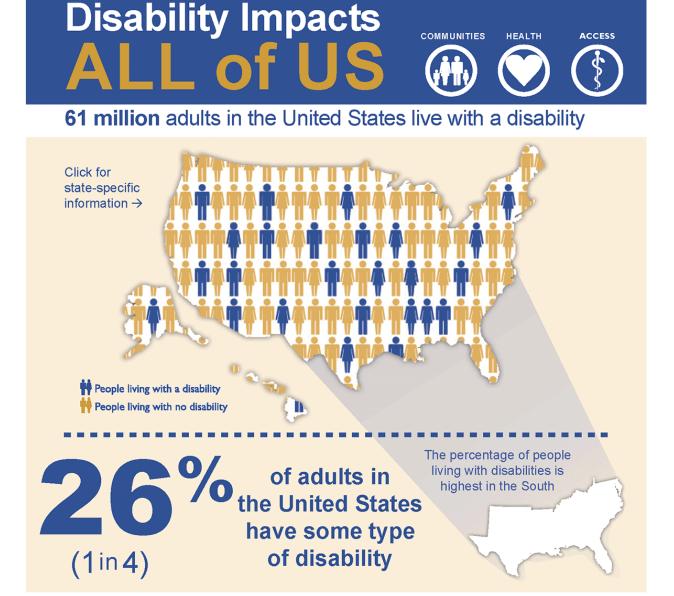
# **Expectations & Imaginations**



"I just think it's best practice to not treat all medical students like we're supposed to be super healthy in [contrast to] all these patients out there who are the people with all of these real problems that we have to solve. I wish instructors would take a more realistic view of the fact that most of the learners in this room have been patients."

## – Renee (MD Program)





https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

# Disabling "who's in the room?"



# Roadmap

## 1. The process of "disabling"

## 2. Disabling bioethics

-Ouellette & Scully

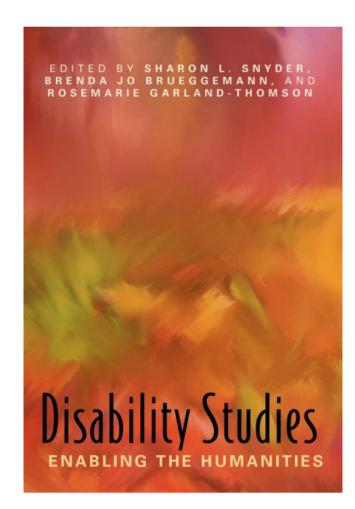
## 3. Who's in the room? Taking on new perspectives

-Disability gain

- -Disability as unsurprising
- -Resources and best practices

# The Process of "Disabling"

### Embracing disability as a critical category for reflection



# **Disabling Bioethics**



### BIOETHICS AND DISABILITY

Toward a Disability-Conscious Bioethics

Alicia Ouellette

**BIOETHICS FOR THE PEOPLE** 

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TRANSHUMANISM, DISABILITY, AND BIOPOLITICS

**MELINDA C. HALL** 

About Episodes Contact

### **Disability Bioethics**

### Disability Bioethics

This episode Devan and Tyler talk about disability with professor <u>Joseph Stramando</u>. They also discuss <u>Crip</u> <u>Camp</u>, a documentary on Netflix, and learn what disability studies and disability philosophy contribute to bioethics.

### Read more of Dr. Stramando's published works:

 "Not Who, But What Professional Bioethicist: <u>Should Prioritize When Responding to the</u> <u>Covid-19 Pandemic</u>"

 "<u>Disability and the Damaging Master Narr</u> of an Open Future"



Disability Bioethics

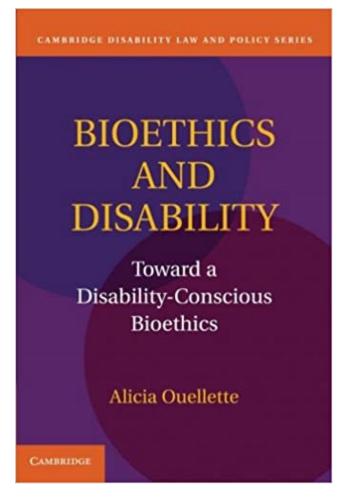


Jackie Leach Scully

# **Disabling Bioethics**

"If I were listing the most dangerous people in the U.S. today, bioethicists ...would top my list – way above skinheads, whose beliefs they appear to share."

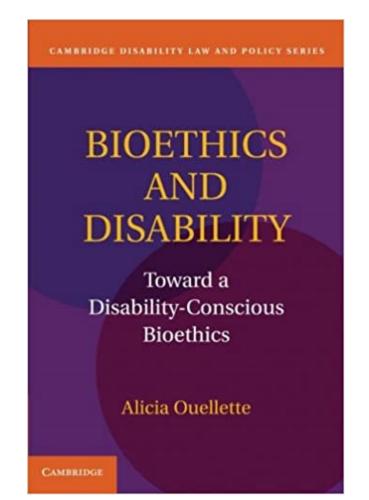
-Alice Mailhot



# Ouellette

# Questions of method and disability

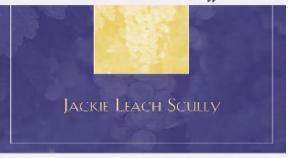
- Individuals with disabilities and individualized interventions and technologies?
- Or, communal and collective concerns and interventions?



# Scully



Moral Bodies, Moral Difference

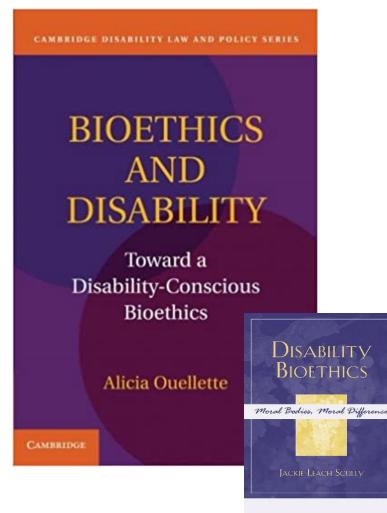


## "the ethics of disability"

VS.

### "disability ethics"

## **Disabling Bioethics**



Serious ethical analysis must be informed by the "embodied effects of impairment" – the embodied wisdom of disabled people

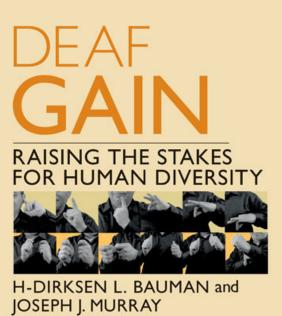
# Disability consciousness requires concrete collaborations



## Diversifying "who's in the room" among learners and trainees







Editors

Foreword by ANDREW SOLOMON Afterword by TOVE SKUTNABB-KANGAS "The biological, social, and cultural implications of being deaf are not automatically defined simply by *loss* but could also be defined by *difference*, and, in some significant instances, as *gain*." "You know the lecturer worked in OB/GYN or something and was trying to answer questions and really couldn't. She basically said, 'yeah, this is rare, you're not really gonna see it.' And it made me feel so upset. I felt so deflated. We're training clinicians – this is important. And this is my life! I was so upset that I had to follow-up and educate people on it."

-Callie (PA Program)



# **Disability as unsurprising**

### DISABILITY *and* Christian Theology

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Embodied Limits and Constructive Possibilities

- CO

DEBORAH BETH CREAMER



"My advisor knows about accommodations. She was very much like, 'this is not a weird thing; this is not a thing we've done before, but this is something we can absolutely do."

-Callie (PA Program)

# **Existing Resources**



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Review > J Pediatr Rehabil Med. 2020;13(3):393-404. doi: 10.3233/PRM-200763.	FULL TEXT LINKS	
COVID-19 and the need for disability conscious	IOS Fress Full Text	SECOND EDITION
medical education, training, and practice	ACTIONS	EQUAL ACCESS
Adrienne Doebrich <sup>1</sup> , Marion Quirici <sup>2</sup> , Christopher Lunsford <sup>3</sup>	66 Cite	FOR STUDENTS
Affiliations + expand	ය Favorites	
PMID: 33252100 DOI: 10.3233/PRM-200763	SHARE	WITH
Abstract		DISABILITIES
The COVID-19 era exposes what was already a crisis in the medical profession: structural racism, ageism, sexism, classism, and ableism resulting in healthcare disparities for Persons with		DIGADILITILO
Disabilities (PWD). Early research highlights these disparities, but we do not yet know the full	PAGE NAVIGATION	The Guide for Health Science
impact of this pandemic on PWD. Over the last 20 years, many medical schools have attempted to develop disability competency trainings, but discrimination and inequities remain, resulting in a pervasive distrust of medicine by the disability community at large. In this commentary, we suggest	< Title & authors	and Professional Education
that disability competency is insufficient because the healthcare disparities experienced by PWD	Abstract	T M. M
are not simply a matter of individual biases, but structural and systemic factors requiring a culture shift in the healthcare professions. Recognizing that disability is a form of diversity that is	Similar articlae	Lisa M. Meeks Neera R. Jain Elisa P. Laird



Association on Higher Education And Disability<sup>®</sup>

EDITORS

# **Existing Initiatives**



# Asking and answering the question "who's in the room?"



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# Questions? Contact Me sarah.j.barton@duke.edu

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