



Disability Culture: Diversity, Inclusion, & Disability Justice

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Overview of Presentation

- ◆ **Basic Principle: Disability is a part of diversity, and including disabled people in the classroom & concert hall benefits everyone.**
- ◆ **Language about disability**
- ◆ **Contrasting models of disability: Medical, Charity, & Social**
- ◆ **Ableism: Overcoming or Acceptance?**
- ◆ **What is Disability Justice?**
- ◆ **Conclusion: Concrete Suggestions to transform your teaching, scholarship, & performance to advance the goals of Disability Justice.**

A Bit About Me...

- ◇ **I am a musicologist & disability activist. My pronouns are she/her/hers.**
- ◇ **I am a multiply disabled person: I am autistic (and therefore neurodivergent), and I have chronic health disabilities, which is why I use a cane or crutches. I also have a history of PTSD.**
- ◇ **My disabilities used to be invisible, but they have become increasingly visible since Fall 2016.**
- ◇ **I tend to use identity-first language, and I do refer to myself as a crip.**
- ◇ **I actively work on inclusive pedagogy, confronting Academic Ableism, and incorporating the principles of Disability Justice into higher ed.**

Language About Disability

- ◇ **Person-First Language (person with a disability)**
 - ◇ **From the ARC: "People-First Language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person."**
- ◇ **Identity-First Language (disabled person)**
 - ◇ **From Autistic Hoya: "Yet, when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person.[...]Ultimately, we are accepting that the individual is different from non-Autistic people--and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference."**
- ◇ **Good Rule: Mirror the individual's terminology!**
 - ◇ **Don't tell a disabled person how to refer to themselves or their community.**
 - ◇ **Avoid Euphemisms: #SayTheWord [Disability is not a bad word!]**

Additional tips on language:

- ◆ **You can have health conditions, etc. without identifying as disabled.**
- ◆ **Some communities embrace the label, and some reject it. For example, deaf v Deaf. For example, there is a lot of variation within d/Deaf and the Little People communities.**
- ◆ **You do not have to publicly identify as disabled, and you do not have to disclose your disabilities to the world.**
- ◆ **Some slurs such as “cripple” (crip/krip) are being reclaimed; however, that doesn’t mean you should use those terms for others.**
- ◆ **Some slurs (for example, “retard”) are never okay**
- ◆ **Avoid language that is infantilizing or condescending; adults with intellectual disabilities do not have the mind of a child, and mental age is not an accurate or empathetic model.**

Some categories of disability...

- ◇ **Deaf vs deaf vs HOH vs Auditory Processing Disorder**
 - ◇ **Deaf people make and enjoy music! This is a common misconception.**
- ◇ **Intellectual & Developmental Disability (I/DD)**
 - ◇ **Ex: Autism is a Developmental Disability**
 - ◇ **Ex: Down Syndrome is an Intellectual and Developmental Disability**
- ◇ **Physical Disabilities [see also: manual wheelchairs vs power wheelchairs]**
- ◇ **Chronic Health Disabilities, Mental Health Disabilities**
- ◇ **What are some other categories/terms you've heard?**

So then... What is Disability?

- ◇ **“An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”**
- ◇ **“Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.”**
- ◇ **Categories of disability shift culturally, historically, and technologically: access to glasses, medications, transportation infrastructure affect how disabled someone is (or is perceived to be)**

The Medical Model of Disability

- ◇ **The Americans with Disabilities Act (1990) defines disability in a very medical way, using language like “impairment”**
 - ◇ **Impairment: physical or psychological lack or loss of function**
- ◇ **The Medical Model understands Disability as a biological deficit**
- ◇ **The “problem” of disability is located in the individual’s bodymind**
 - ◇ **Bodymind is a term that recognizes that our minds are part of our bodies; mental illness affects the rest of the bodies and “physical” illness affects our minds.**
- ◇ **The “solution” is to fix the individual’s bodymind (cure ideology)**
- ◇ **This is most likely the way you were taught to think about disability**

Corollary: the Charity Model

- ◇ **A consequence of the Medical Model is the Charity Model, in which nondisabled people work to better the lives of disabled people through charity. Disability Professionals & family often direct these efforts.**
- ◇ **This may seem like a good thing, but nondisabled people often don't understand what disabled people want & need. Even doctors who work with us significantly underestimate our quality of life.**
- ◇ **The Charity Model leaves disabled people in a position of weakness, contributing to the infantilization & exclusion of disabled people.**
- ◇ **We can see this in action with disability advocacy awards being given primarily to nondisabled people; "prom-posal" videos featuring a nondisabled student inviting a disabled classmate to the dance; some Buddy programs**
- ◇ **This cartoon inverts the paradigm to demonstrate the pitfalls of the Medical & Charity Model; in it, wheelchair users are the majority and those who walk are the minority: <https://youtu.be/4liF-zuwGxE>**

HELP THE ABLI BODIED



Committees are formed. Many people are worried about what becomes known

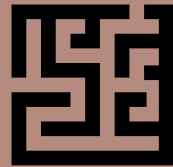
What is the Alternative?

- ◆ **The Social Model of Disability states that there is natural variation in human bodyminds. Disability is produced socially from barriers that prevent full participation in society based on a minority bodymind difference.**
- ◆ **The “problem” of disability is located not in the individual but in the inaccessibly-built environment; this can be a physical, social, sensory, economic, linguistic, or other kind of “environment”**
- ◆ **The “solution” is to eliminate social and structural barriers, to improve access for all types of bodyminds.**
- ◆ **Thinking about glasses: Technically, if we wear glasses, we have a vision impairment in the Medical sense. However, if we can access glasses (financially, socially, etc.), we are no longer disabled by it.**
- ◆ **Similarly, access to healthcare, medications, transportation infrastructure, education, therapy, respect, and dignity can reduce exclusion.**

SOCIAL MODEL OF DISABILITY



Disability: socially produced barriers that prevent full participation in society of people with impairments.



Environments are built to favor some bodies/minds over others



“...disability is not bodily insufficiency, but instead arises from the interaction of physical differences with an environment” – Garland-Thomson



Does not deny pain, illness, and impairment, or argue against medical treatment; but focus is on addressing barriers. [common misconception]



Social barriers include: inaccessible buildings, services, language, communication; prejudice, discrimination; institutional exclusion

What is Ableism?

“Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other. Ableism is intertwined in our culture, due to many limiting beliefs about what disability does or does not mean, how able-bodied people learn to treat people with disabilities and how we are often not included at the table for key decisions.”

Leah Smith, for the Center for Disability Rights (CDRNYS.org)



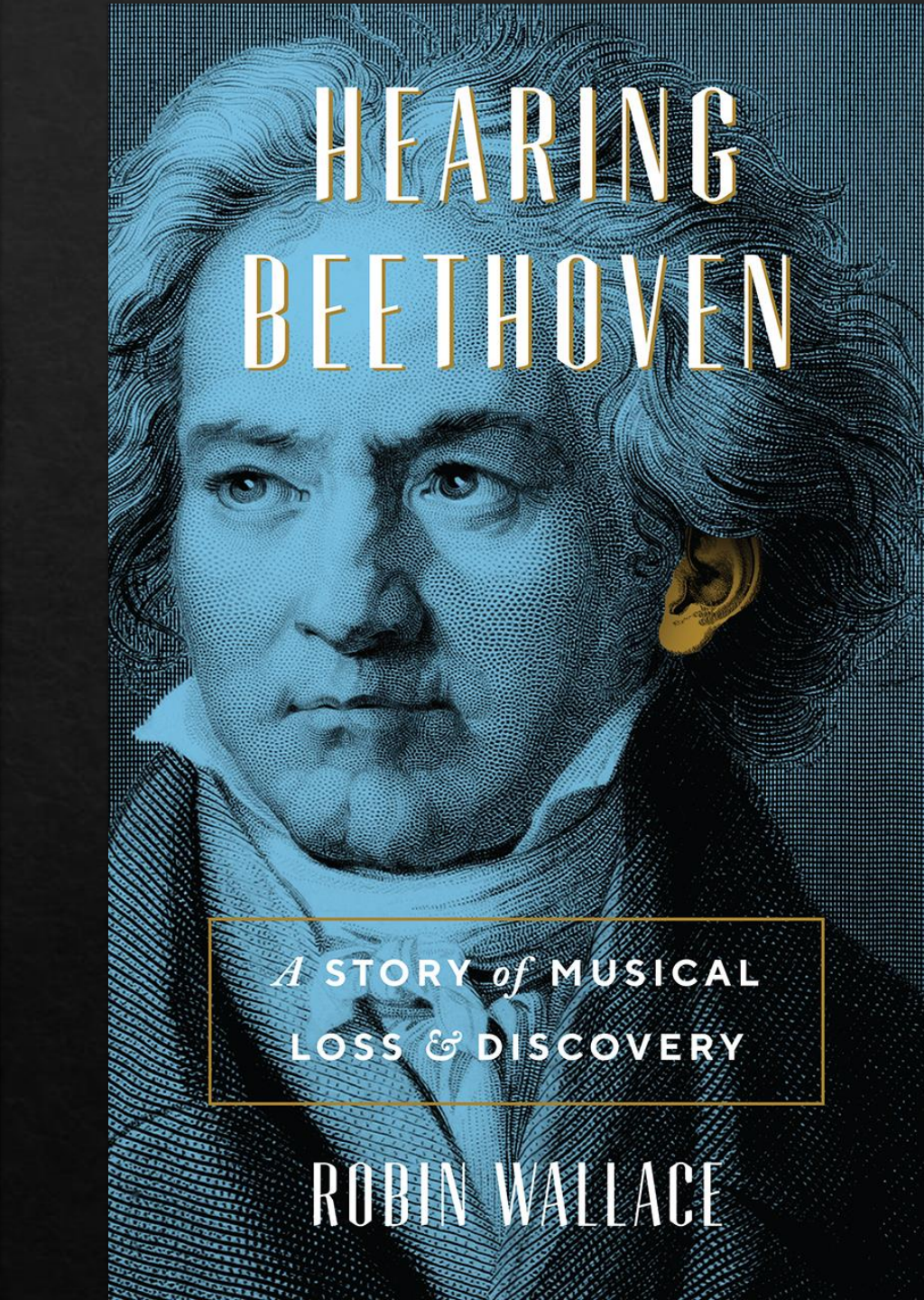
Inspiration Porn & Overcoming

What do they mean?

- ◇ **Inspiration Porn? Reducing disabled people to objects that exist to inspire not-yet-disabled folks.**
- ◇ **Ex: if a disabled person can live their lives, what do you have to complain about? Also: tokenization**
- ◇ **Overcoming narratives: stories of people "beating" their disability, a good attitude erases disability**

What's wrong with them?

- ◇ **Dehumanizes & objectifies**
- ◇ **What we overcome is ABLEISM**
- ◇ **Our bodyminds should be celebrated, they are part of the diversity of the human experience**
- ◇ **Shifts the problem to the person rather than society: "No amount of smiling at a flight of stairs has ever made it turn into a ramp."**



HEARING BEETHOVEN

A STORY of MUSICAL
LOSS & DISCOVERY

ROBIN WALLACE

We need to talk about Beethoven...

- ◆ Beethoven experienced hearing loss as early as 1796; in 1802, friends notice & he writes the Heilingendstadt Testament to his brothers
- ◆ Not just “loss”: distortions, tinnitus, loudness recruitment; fluctuations
- ◆ We often teach Beethoven as a musical genius who overcame the loss of his hearing, but this isn't the whole truth... And it is a dangerous myth!

Heilingenstadt Testament

- ◇ **We often teach the Heilingenstadt Testament in the context of deafness's effect on his ability to perceive music; however, that is not what Beethoven describes as disabling for him.**
- ◇ **Reputation & stigma: Beethoven was concerned that enemies would undermine his work, damage his career if they could use his deafness against him; high cost of Masking**
- ◇ **Social impact: difficulty having conversations in noisy environments, particularly while he felt pressured to keep it a secret**
- ◇ **Perceptions of his mood/emotions/personality: "Oh you people who take me for hostile, obstinate or misanthropic... you do me a great injustice. You do not know the secret of what makes me appear that way."**
- ◇ **Perception of self: Beethoven's alcoholic father exploited him as a child prodigy (but he didn't quite live up to Mozart), and internalized ableism is THE WORST (citation: personal experience)**

Beethoven's Style as a Consequence of Embracing his Deafness

- ◇ Relied extensively on writing as his hearing grew worse (sketchbooks)
- ◇ Muscle memory, physicality of improvisation at the piano; physical bond with the instrument
- ◇ New musical textures created with his eyes, pushing audiences to understand more complex sonorities (ex, *Grosse Fuge*, op. 133)
- ◇ Unprecedented use of short, memorable fragments
- ◇ Long, complex musical structures because they could be planned visually and built from those short memorable fragments
- ◇ Increasingly rhythmic motives (middle into late period)

Disability Rights: Nothing About Us Without Us

- ◇ **The Disability Rights movement emerged with particular force in the United States in the latter half of the twentieth century.**
- ◇ **Independent Living Movement, Ed Roberts – CILs today (incl AACIL)**
- ◇ **Deaf President Now!, Gallaudet University**
- ◇ **504 Sit-ins, Judy Heumann, and the ADA (*Crip Camp!*)**
- ◇ **ADAPT (if you see disabled folks being arrested, it's usually them)**
- ◇ **BUT: overwhelmingly White leadership, single-issue, and prioritizing certain disabilities (wheelchair users, Deaf, etc. but not I/DD)**

Disability Justice



Disability Rights

Disability Justice Framework

- ❖ All bodies are unique and essential.
- ❖ All bodies have strengths and needs that must be met.
- ❖ We are powerful, not despite the complexities of our bodies, but because of them.
- ❖ All bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them.

SKIN, TOOTH, AND BONE

The Basis of Movement is Our People



A Disability Justice Primer
by Sins Invalid | Second Edition

Ten Principles of Disability Justice

- ◆ **Intersectionality**
- ◆ **Wholeness**
- ◆ **Cross-Movement Organizing**
- ◆ **Cross-Disability Solidarity**
- ◆ **Anti-Capitalism**
- ◆ **Sustainability**
- ◆ **Interdependence**
- ◆ **Collective Access**
- ◆ **Collective Liberation**
- ◆ **Leadership of Those Most Impacted**



Leroy Moore & Krip Hop Nation “The Untold Story: Disabled Black Boyz”

**Every protest don't pass the test
BLM before White grants set in
Disabled Black boys
was always outside looking in
ADAPT came at me about curb cuts
While disabled Black boys were getting shot up
What's up with that 2019 it's the same old crap
Disabled Black Boys
It's up to you to get read of that noize
Drown it out with Rob Da Noize**

Rising Phoenix

(2020)

Krip Hop Nation:

- ◆ **Toni Hickman**
- ◆ **Georgetragic**
- ◆ **Keith Jones**

<https://youtu.be/3bnTmlpHlsl>



A NETFLIX ORIGINAL DOCUMENTARY

R I S I N G
P H O E N I X

26 AUGUST | NETFLIX

**Gaelynn
Lea**



Gaelynn Lea Tressler "I Wait"

**Did you know that
When I get angry
I breathe fire
I could burn this place down?**

**You may not realize
All of the small ways
I am not welcome
But just take a look around**

**Still everybody knows
That you need a place to go
And livin' isn't easy
If you incinerate your home**

**THURSDAY, JANUARY 16
STAMPS AUDITORIUM, 7:00 PM
FREE, NO TICKETS REQUIRED**

Practical Suggestions

- ◇ **Let disabled folks lead! If you don't know any, think about why. Follow disabled leaders on social media and listen.**
- ◇ **Teach disabled musicians, teach them as disabled, let them be whole and fully present in your curriculum.**
- ◇ **Hire disabled musicians, scholars, and students. Pay them a fair wage and accommodate them. Believe them when they tell you what they need.**
- ◇ **Collaborate with cultural centers and other departments to bring LGBTQ+ BIPOC disabled artists & scholars to your university.**
- ◇ **Practice Interdependence: collaborate with disabled scholars, team teach, and create a healthy sustainable culture in your department.**
- ◇ *Find the community, ask what they need, and do what you can.*

People & Hashtags to Follow

- ◇ **Alice Wong, Disability Visibility Project: podcast, website, book**
- ◇ **Academic Ableism & Universal Design for Learning: Jay Dolmage**
- ◇ **Disability Culture at the University of Michigan (DC@UM)**
- ◇ **#AcademicAbleism #WhyDisabledPeopleDropOut**
- ◇ **#AccessFails #AccessFail #AccessibilityFail #AccessIsLove**
- ◇ **#DisabilitySoWhite #DisabilityTooWhite #AbleDsAreWeird**
- ◇ **#ActuallyDisabled #ActuallyAutistic #ThingsDisabledPeopleKnow**
- ◇ **#A11y #CripTheVote #DisabilityUMich**

Next time: Access!

“When I think about access, I think about love. I think that crip solidarity, and solidarity between crips and non(yet)-crips is a powerful act of love and I-got-your-back. It’s in big things, but it’s also in the little things we do moment by moment to ensure that we all – in all our individual bodies – get to be present fiercely as we make change.

Embedded in this is a giant paradigm change. Our crip bodies aren’t seen as liabilities, something that limits us and brings pity, or something to nobly transcend, ‘cause I’m just like you. Our crip bodies are gifts, brilliant, fierce, skilled, valuable. Assets that teach us things that are relevant and vital to ourselves, our communities, our movements, the whole goddamn planet.”

Leah Lakshmi Piepzna-Samarsinha, *Care Work*, 75.



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Disability Day of Mourning March 1, 2021 at 7pm

- ◆ DC@UM's vigil has moved online. It will be presented in partnership with the Disability Alliance and Caucus at Virginia Tech.
- ◆ Disability Day of Mourning is an annual day of remembrance for disabled people who have been murdered by family members & caregivers. We honor those we have lost as a community, affirming their humanity in defiance of systemic ableism.
<https://disability-memorial.org/>
- ◆ ASL & CART provided; working on an on-site counselor in a separate Zoom room
- ◆ *Mourn for the dead & fight like hell for the living*

Additional Resources

- ◇ **Sins Invalid, *Skin, Tooth, and Bone: The Basis of Movement is Our People, A Disability Justice Primer*, second edition (2019), [link to purchase](#)**
- ◇ **Leroy Moore, *Black Disabled Ancestors*, POOR Press (2020), [link to purchase](#)**
- ◇ **Leroy F. Moore, Jr. "Black Disabled Ancestors Can't Rest in Peace Until We Write the Whole Story," *Peace Review: A Journal of Social Justice* 31, no. 4 (2019): 515-519, DOI: [10.1080/10402659.2019.1800938](https://doi.org/10.1080/10402659.2019.1800938)**
- ◇ **Sins Invalid's Website: <https://www.sinsinvalid.org/>**
- ◇ **Krip Hop Nation's Website: <http://kriphopnation.com/>**
- ◇ **Wheelchair Sports Camp's Website: <http://wheelchairsportscamp.co/>**
- ◇ **Gaelynn Lea Tressler's Website: <https://violinscratches.com/>**

Suggested Disabled Musicians*

Leroy Moore Recommends:

- ◇ Curtis Mayfield
- ◇ Rob Da' Noize Temple
- ◇ Keith Jones
- ◇ Blind Willy Johnson
- ◇ Toni Hickman
- ◇ Wheelchair Sports Camp

Gaelynn Lea Recommends:

- ◇ Lachi
- ◇ Velvet Crayon
- ◇ Kalyn Heffernan
- ◇ Vic Chesnutt
- ◇ Tabi
- ◇ Andy Slater

***Both Leroy Moore & Gaelynn Lea Tressler were put on the spot! But these artists came to mind.**