Forging a New Future

Introduction by Deana Herrman, PT, PhD and Resource List by Deana Herrman, PT, PhD; Sarah Caston, PT, DPT; and Priyanka Bhakta, DPT

INTRODUCTION

I met pioneering disability rights activist Judy Heumann once. Our brief meeting coincided with a lobbying action event by a disability rights organization to encourage the United States Congress to pass the Disability Integration Act,¹ a bill to legislate more choice in utilizing home and community-based services. My daughter, a curious disabled pre-teen, attended the event as a media intern with the organization and had a chance to interview Ms. Heumann. I was the parent along for the ride. Realizing Ms. Heumann was likely sitting for her millionth unpaid interview, after they finished speaking I went over to thank her. Ms. Heumann told me that my child was "amazing" and "the future." I swelled with pride and expressed gratitude for her time, her work, and her overall availability and accessibility to inspire the next generation of disabled youth to make society live up to the values of inclusion and access.

In that moment of pride when the mother of the disability rights movement recognized my daughter's drive and promise, I also felt like I was hiding a secret. I was late to realize the importance of disability rights and justice, disability identity, disability community, and I was a physical therapist. By this point I was aware of the criticism of rehabilitation related to disability.²⁻⁶ Judy Heumann's own history with physical therapy at

school briefly describes a less than inclusive environment resulting in decreased instructional time at school and separation from peers.⁷

Still Fighting for Justice

While a common call is "the future is accessible," a reality is that the future is disabled.^{8,9} Disability is not simply erased with access. Disabled people are still working toward realizing their rights and achieving justice. Another reality is that physical therapy has perhaps been a bit slow to support the advocacy work and expertise of disabled people. Instead, it has been upholding ableist norms that may actually have stifled progress toward an accessible future.^{2-6,10-17}

WHAT CAN WE DO RIGHT NOW?

As we think about the immediate future where bodily autonomy is on the line; the Affordable Care Act's protections may be stripped; and environmental disasters may cause precarity, disablement and loss; what do we as physical therapists do to ensure an equitable, accessible, and inclusive future for all? How can we respectfully and genuinely honor the knowledge and expertise of disabled people in our own work to move us toward an anti-ableist practice?

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Judy Heumann is a prominent figure in this resource list. She has authored books, participated in podcasts, is revered in a historical perspective, and is a central figure in the 2020 documentary, *Crip Camp*.¹⁸ For some people, *Crip Camp* was the entry point to learning about disability history—and the power of the disability community. We need to know history, so we avoid future mistakes, recognize who is missing from that history, and where we need to fill in gaps of knowledge.

Ms. Heumann's trust in the future generation of disabled youth driving messages of access, inclusion, and anti-ableism forward weighs on me as someone who has watched their own disabled child navigate inaccessible systems and spaces; seen my disabled college students redefine paths to become healthcare providers; and felt the impact of the disability community in changing language, events, societal views, and policy.

A Starting Point: Educational Resources

While this resource list originated out of the Access Summit as a take-home tangible piece of info for attendees, it is important that we think about what we will do with these resources to influence the future. This list is not comprehensive; the authors may provide an updated list in the final part of this special issue series of *JHR*. There is a lot on our to-do list, and perhaps it seems overwhelming. Luckily, resources here give you a path forward.^{9,14,19-21}

HOW TO BEGIN...

Below are suggestions to help you navigate the resource list:

- **Reflect.** First, know your starting point in relation to disability. Consider if you are informed solely by being a physical therapist and what that can mean for your understanding of disability. Are there any biases, comfort, or discomfort you have around ability and disability? Name them.
- Educate yourself. Plan to learn about disability and learn about it perhaps in a way that you hadn't before. Read narratives, attend art shows by disabled artists, or attend other disability cultural events. For those of you at universities, disability cultural centers may offer additional spaces in which to learn. Attend bias trainings, journal clubs, informal discussions; watch film/media about disability history and rights. Attend disability culture and justice events.
- **Recognize.** Can you identify ableism? What do you think your role is in addressing ableism? Recognize who is present and who isn't in discussions, and what media or literature you are consuming to educate yourself.
- Integrate new knowledge into everyday practices. Take what you learn and question what you do. How does the social model of disability or disability justice, or how do resources like this one, get brought to our profession to influence it? Ensure representation of disabled people across educational and practice contexts. Amplify disabled voices and stories. What can we do with personal narratives beyond just being "aware" that persons with disabilities have rich, full lives but also

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still face challenges in society across all areas of work, life, and leisure?

...FORGING A NEW FUTURE FOR THE PROFESSION

As physical therapists we are expected to be lifelong learners; this applies to learning about disability and ableism as well. It is never too late to start, and it is always okay to keep learning, recognize when we don't know enough, and strive to do better – for the future.

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ANTI-ABELISM RESOURCE LIST

Books

Disability Visibility - Alice Wong

Year of the Tiger – Alice Wong

Disability Intimacy - Alice Wong

Brilliant Imperfection – Eli Clare

Golem Girl (memoir) - Riva Lehrer

Haben: The Deafblind Woman Who Conquered Harvard Law – Haben Germa

Exile & Pride: Disability, Queerness, and Liberation (Duke University Press, 2015) – Eli Clare

The Anti- Ableist Manifesto: Smashing Stereotypes, Forging Change, and Building a Disability- Inclusive World – Tiffany Yu

Demystifying Disability - Emily Ladau

Normal Sucks: How to Live, Learn and Thrive Outside the Lines – Jonathan Mooney

The Pretty One – Keah Brown

Easy Beauty – Chloe Cooper Jones

Just Care – Akemi Nishida

Being Heumann – Judy Heumann

Care Work - Leak Lakshmi Piepzna-Samarasinha

Black Disability Politics - Sami Schalk

Feminist Queer Crip – Alison Kafer

Marbles: Mania, Depression, Michelangelo & Me – Ellen Forney

Capitalism & Disability - Marta Russell

How to Tell When We Will Die: On Pain, Disability and Doom – Johanna Hedva

We're Not Broken: Changing the Autism Conversation – Eric Garcia

McBride, J The Heaven & Earth Grocery Store (fiction)

True Biz – Sara Novic (fiction)

Good Kings Bad Kings: A Novel – Susan Nussbaum

The Anti-Ableist Manifesto - Tiffany Yu

Why I Burned My Book & Other Essays on Disability – Paul Longmore

Visual Arts/Art History

Riva Lehrer

Ted Meyer

Disabled Musicians

Stevie Wonder

Ray Charles

Django Reinhardt

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Rick Allen (Drummer from Def Leppard)

Beethoven

Itzhak Perlman

Eric Howk

The Ying Yang Twins

Jacqueline du Pré

Ren

Lewis Capaldi

Halsey

The Blind Boys of Alabama

Social Media/Podcasts

Alice Wong @disability_visibility (IG)

Cole Sydnor @Roll.with.Cole (IG)

Jessica Blinkhorn @Spankbox.atl (IG)

Imani Barbarin @crutches_and_spice (IG)

Sins Invalid @sinsinvalid (IG) (website)

Ellie Goldstein @elliejg16_zebedeemodel (IG)

Chella Man @chellaman (IG)

Lauren Spencer @itslololove (IG)

Mia Mingus @miamingus (IG)

The Disability Tangent Podcast

The Heumann Perspective Podcast

The Disability Visibility Project (link)

News Media

Johnson, H. M. Unspeakable conversations. New York Times. (2003, February 16).

New York Times' Disability Column

DISABLED JOURNALISTS WHO COVER DISABILITY:

Eric Michael Garcia

Sara Luterman

Film and Television

Crip Camp (documentary)

Code of the Freaks (documentary)

Fixed: The Science/Fiction of Human Enhancement (documentary)

Reelabilities (film festival)

Comedy Central's <u>Drunk History: Section 504 Rehab</u> <u>Act</u> (sketch comedy)

Speechless (series, ABC)

Special (series, Netflix)

Sex Education (series, Netflix)

Advocacy Organizations

Diversability (website link)

Talila A. Lewis (website link)

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American Association of People with Disabilities (AAPD)

American Disabled for Attendant Programs Today (ADAPT)

National Council on Independent Living (NCIL)

Disability Justice & Anti-Ableism Catalyst group of the <u>APTA</u> (DJAAC)

Chicagoland Disabled People of Color Coalition (website)

Disability Lead (website)

Autistic Self Advocacy Network (ASAN)

Critical Disability Studies Texts

Ellis, K., Garland-Thomson, R., Kent, M., & Robertson, R. (Eds.). (2019). *Manifestos for the future of critical disability studies* (Vol. 1). Oxon: Routledge.

Gibson, B. (2016). *Rehabilitation: A post-critical approach*. CRC Press.

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The Disability Studies Reader, Lennard J. Davis, 2015

Keywords for Disability Studies, edited by Rachel Adams, Benjamin Reiss and David Serlin, 2015.

Disability as diversity: A guidebook for inclusion in medicine, nursing, and the health professions. Meeks, L. M., & Neal-Boylan, L. Springer (2020)

Herrman, D., Sharp, A., ... & Berg, K. (2024). Dismantling Ableism in Interprofessional Medical Education to Promote Health Equity for People With Disabilities. Eds. Bonilla-Silva, Haozous, E, Meeks, L., et al. In: *Reimagining Medical Education: The Future of Health Equity and Social Justice. The AMA MedEd Innovation Series.* Elsevier:Philadelphia, PA; 63-74.

SUGGESTED SEARCH TERMS FOR ACADEMIC RESOURCES

- ableism
- anti-ableism
- disability
- access or accessibility
- accommodation
- disability rights
- accommodation
- disability justice

About the Authors



Deana Herrman PT, PhD is an assistant professor in the Doctor of Physical Therapy program at Northern Illinois University. Her research incorporates disability studies principles to examine practices in physical therapy and health professions education, and healthcare interventions and practice. Deana believes the humanities should be an integral part of health professions to foster a praxis of reflection, openness and change to better meet societal health needs.



Sarah Caston, PT, DPT is an assistant professor and assistant director of clinical education at Emory University's Doctor of Physical Therapy Program. Dr. Caston is an alumnus of Emory University's DPT Program and received her bachelor's degree in Rehabilitation Science from the University of Pittsburgh. She serves on the American Council of Academic Physical Therapy's Consortium for the Humanities, Ethics and Professionalism, and chairs its Diversity, Equity, and Inclusion Committee. As a clinical educator, Dr. Caston weaves humanities' focus and narrative reflections into her teaching of geriatric and neurologic rehabilitation. She has a deep interest in helping students explore their perspectives, and challenge biases, through the incorporation of narrative reflections and humanities-based creative work. In a course co-developed with Dr. Sarah Blanton, Beyond the Diagnosis: Psychosocial Topics in Rehab Through the Lens of the Humanities, Dr. Caston promotes self-exploration and professional formation utilizing narrative and engagement in the humanities. She co-directs Emory DPT's Learning Community Program, which promotes student-faculty connections, and directs research on practical methods for improving student well-being. Dr. Caston's scholarly interests include the intersection of the lived experience of individuals with rehabilitation, education and practice, ethics in rehabilitation, and DPT student well-being. She is passionate about social justice and promotes humanities practices and student self-reflection around the lived experiences of individuals in marginalized populations.

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