

Structural Ableism and Interpersonal Discrimination as Fundamental Determinants of Physical and Mental Health for Disabled People in the United States: A Working Paper

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Slide 1: Introduction

Good morning. My name is Dielle, and I use she/her or ze/hir pronouns. I am a white, transfeminine person with wavy hair wearing a gray dress and standing at the podium with my walking sticks. I am excited to share with you today about my research exploring structural ableism and health in the United States. For those who would benefit from a transcript of this talk, you can find one at the link on the screen.

Slide 2: Positionality

This work is part of a larger collaboration between me and Dr. Jess Chen. Our photos are on the screen. I am a disabled, neurodivergent, transfeminine person. I am a white settler and identify within the queer, crip, and mad communities. I am a research fellow at Boston University School of Public Health and was previously affiliated with the University of Washington School of Public Health. Dr. Jess Chen is a 2nd-generation Taiwanese-American cisgender woman with lived experience of disability. She is a clinical psychologist in the Pain Rehabilitation program at the VA Puget Sound Health System and an Assistant Professor at the University of Washington School of Medicine. We are also grateful to several co-authors for providing analytic support for this working paper including Dr. Yana Vierboom, Rafeya Raquib, and Dr. Andrew Stokes.

Slide 3: Opening Observation

I want to start today with an observation.

Disability is often framed by health systems as a problem to be cured medically, even though many disabled, neurodivergent, and mad people would prefer policies to make society more accessible to us and other changes to improve our quality of life.

So... why are health systems like this?

Slide 4: Structural Ableism in Health Systems

Dr. Chen and I explored this question in our article "Structural ableism in public health and healthcare: a definition and conceptual framework" published in February.

In this article, we reviewed literature by disability studies and disability justice scholars and advocates who have previously written about ableism — such as Subini Ancy Annamma, Patty Berne, Nicole Brown, Carli Friedman, TL Lewis, Mia Mingus, and Sins Invalid.

Slide 5: What Is Structural Ableism?

In the article, we describe structural ableism "as a system of historical and contemporary policies, institutions, and societal norms and practices that devalue and disadvantage people who are disabled, neurodivergent, chronically ill, mad, and/or living with mental illness and privilege people who are positioned as able-bodied and able-minded."

Slide 6: How Does Structural Ableism Operate?

When it comes to how structural ableism operates, we write that "structural ableism denies disabled communities equitable access to social resources and to disability competent and affirming health services, control over whether their experiences are listened to and believed, autonomy over how their needs are represented and responded to, and justice when they are exposed to harm, discrimination, and violence."

Slide 7: How Is Structural Ableism Upheld?

Finally, as disability justice scholars and advocates have long pointed out, "structural ableism is upheld via interlocking systems of power and oppression, such as racism, sexism, transphobia, capitalism, and colonialism, and operates alongside audism (which is discrimination against people who are d/Deaf and hard of hearing), sanism, and other types of disability-related bias and discrimination including internalized and interpersonal ableism."

Slide 8: Pathways Between Structural Ableism and Health

The primary contribution of our prior article was our conceptual framework, in which we identified numerous pathways through which structural ableism may influence health for people impacted by ableism. This framework is visualized in the figure on the screen.

In this figure, we describe a number of upstream pathways such as social, economic, health, and other policies, sociocultural attitudes and depictions of disability, exclusion of disabled people from health decision-making and research, reliance on the biomedical model of disability, and legacies of eugenics and institutionalization that pervade health systems.

We also describe some more proximate pathways such as disability incompetent and non-affirming health care, barriers in education, housing and employment, physical and virtual inaccessibility, assault, victimization, and harassment, and carceral and other types of state violence. We also highlighted that each of these pathways may impact health through physiological and behavioral processes such as chronic stress, minority stress, trauma, and health risk behaviors used as coping mechanisms.

In our current study, we focus specifically on health services as just one manifestation of structural ableism.

Slide 9: Why a Focus on Health Services?

So why did we take that focus?

Well, at least 36% of health care expenditures in the U.S. are related to disability (Khavjou et al., 2020). So there is a lot of money to be made by health system actors (most of whom are nondisabled) from researching, developing cures for, pathologizing, and maintaining social and structural determinants that create disability and make living with a disability stressful.

Disabled people in health systems also experience frequent occupational discrimination, leading to systemic exclusion from health care decision-making. Only 3% of physicians report a disability compared to one in four adults who have a disability (Nouri et al., 2021), and less than 2% of NIH funding goes to disabled researchers (Swenor et al., 2020).

Slide 10: Ableism and Health Care Professionals

Prior work by Dr. Carli Friedman and colleagues has also shown that more than 30% of health care professionals hold explicit preferences for nondisabled people over disabled people and the vast majority hold implicit preferences for nondisabled people.

Slide 11: Research Objectives

In our study, we sought to use nationally representative survey data from the Medical Expenditure Panel Survey (MEPS) in 2021 (the year when more detailed measures related to discrimination and health care accessibility were introduced) to ask two research questions.

First we asked: how do experiences of discrimination and inaccessibility in health care vary for disabled vs. nondisabled adults and among disabled adults?

Second we asked: how might we expect health for disabled adults in the United States to change if we were to modify their experiences in health care?

Slide 12: Data and Measures

Our sample included adults 18 years and older who reported at least one health care visit in the last year and completed the necessary questionnaires. There were 9,660 adults in our final analytic sample. Disability was measured using the 6 Census Bureau questions that measure disability as difficulty with hearing, vision, ambulation, cognition, self-care, and/or independent living. Since these measures are used in health policy, they are well-suited for this analysis, which explores whether disparities for disabled people can be reframed as inequities related to ableism. MEPS does not ask about disability as a social and/or political category.

For our analysis, we estimated the prevalence of adults experiencing discrimination and/or inaccessibility in health care settings and estimated the prevalence of health outcomes using marginal predictions based on individual multivariable logistic regression models.

We adjusted for respondent age, sex, proxy status (<1% reported by proxy), racialized identity and ethnicity, educational attainment, family income, Census region, health insurance coverage and type of coverage, and number of health care visits in the last 12 months.

Slide 13: Covariates

We adjusted for insurance and health care visits because those who visit providers more often could experience more discrimination and/or inaccessibility solely due to more visits and time spent in health care settings.

Our rationale for adjusting our models for racialized identity, educational attainment, and income was to better isolate the effects of structural ableism. By adjusting for racialized identity – which incompletely but in part captures exposure to racism – we may produce more conservative predictions of differences by disability status.

Slide 14: Stratification

Ableism, however, may also converge with other systems of power and oppression (e.g., racism, classism) which may manifest as higher prevalence of disability and as increased exposure to discrimination and/or inaccessibility.

To examine how ableism and racism may function together as interlocking systems, we also produced estimates of differences in discrimination and inaccessibility by disability status after stratifying by racialized identity and ethnicity.

Slide 15: Figure 1

We found that adults with a disability seeking health care had a 57% higher risk of having at least one experience of discrimination and inaccessibility in health care compared to adults with no reported disability. Adults with a disability had higher risks for each of the component measures we examined – such as having a discrimination experience in health care, not being listened to by a health care provider, having a provider never or only sometimes spend enough time with them, having a provider never or only sometimes make things easy to understand, not being respected by a provider, having low availability of health care in their neighborhood, and being unable to get to an appointment due to lack of transportation. Disabled adults were also more likely to report a larger number of these experiences than nondisabled adults.

Slide 16: Figure 2

When we stratified by racialized identity and ethnicity, we continued to see differences by disability status. Among adults with a disability, the risk of having one or more of the discrimination and inaccessibility experiences in health care was higher for American Indian or Alaska Native, multi-racial, Native Hawaiian or Pacific Islander, and Black adults and lower for Asian American, Hispanic, and non-Hispanic white adults.

Slide 17: Figure 3

Finally, we examined the association of disability status with mental and physical health outcomes (visualized by the triangles). We also examined the association of having a discrimination and/or inaccessibility experience in health care with mental and physical health outcomes among adults with a disability (visualized by the circles). We see elevated odds of having each health outcome for adults with a disability, and that among adults with a disability, discrimination and inaccessibility experiences were also associated with most outcomes.

Slide 18: Predictions Under Hypothetical Scenarios

Finally, we generated some predictions under hypothetical scenarios.

First, we predicted that the number of adults with a disability experiencing psychological distress would decrease (percent change: -8.6% [95% CI: -11.8% to -5.5%]) if the likelihood of an adult with a disability having one or more discrimination and inaccessibility experiences in health care were reduced to the average level for adults with no reported disability.

Second, we predicted that this decrease in psychological distress would be even larger (percent change: -25.8% (95% CI: -34.4% to -17.3%)) if the likelihood of an adult with a disability having a discrimination or inaccessibility experience were reduced to zero.

Slide 19: Main Findings #1

In summary, we found that disabled adults seeking health care had a much higher risk of having at least one experience of discrimination and inaccessibility in health care.

While more research will be needed to establish causality, we found that hypothetical reductions in discrimination and inaccessibility in health care were associated with improvements in health outcomes among disabled adults.

Taken together, the results of this working paper challenge the prevailing view in health systems that health disparities for disabled people are largely caused by disabled peoples' bodies, minds, and the medical conditions they live with. This study suggests that discrimination, inaccessibility, and ableism in health care settings are also important determinants of health and may be key expressions of structural ableism.

Slide 20: Limitations

This study had several limitations.

First, the study relied on cross-sectional data and retrospective reporting of health care experiences. Use of longitudinal data would allow for greater understanding.

Second, because only one year of data was available with the necessary measures, our analytic sample was small, preventing more granular analyses of subgroups.

Third, MEPS is limited to the civilian noninstitutionalized population. However, many disabled people live in institutionalized environments, and many are incarcerated. Research on ableism in institutionalized settings is also needed.

Lastly, our study was limited to the year 2021, during the COVID-19 pandemic. It will be important to examine changes as the COVID-19 pandemic continues to evolve.

Slide 21: Conclusions

While health care professionals often focus on improving patients' health, this study suggests health system actors need to also consider how they may be harming disabled people by exposing them to discrimination, ableism, and chronic stress in health care settings.

Disabled people deserve to have power and control over our own health care and the health policies that shape our lives on every level. While nondisabled people still frequently hold this power, it is important to acknowledge that this power was in most cases not actually given to them. This power was assumed and taken, and it is time for it to be returned.

Slide 22: Thank You!

Thank you for this opportunity to share my research. My email for any questions is lundberd@bu.edu. As I said before, a presentation transcript and the links I shared today are available at: diellelundberg.com/PAA2024

Other Resources Available There:

- “Structural ableism in public health and healthcare: a definition and conceptual framework” (Lundberg & Chen, 2024)
- “Structural Ableism in Public Health and Health Care: Suggestions for Health Researchers and Policymakers Engaging with Our Article” (Lundberg & Chen, 2024)
- “Mad at/in Health Education” Essay Collection (Lundberg, 2024)

References:

1. Lundberg DJ, Chen JA. Structural ableism in public health and healthcare: a definition and conceptual framework. *The Lancet Regional Health – Americas*. 2024;30. doi:10.1016/j.lana.2023.100650
2. Friedman C, Owen AL. Defining Disability: Understandings of and Attitudes Towards Ableism and Disability. *Disabil Stud Q*. 2017;37(1). doi:10.18061/dsq.v37i1.5061
3. Berne P, Morales AL, Sins Invalid. Ten Principles of Disability Justice. *WSQ: Women's Studies Quarterly*. 2018;46(1):227-230. doi:10.1353/wsqa.2018.0003
4. Lewis TA. Working Definition of Ableism - January 2022 Update. Talila A. Lewis. Published January 1, 2022. Accessed November 22, 2023. <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update>
5. Mingus M. Moving Toward the Ugly: A Politic Beyond Desirability. *Leaving Evidence*. Published February 12, 2011. Accessed February 18, 2023. <https://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability/>
6. Sins Invalid. *Skin, Tooth, and Bone: The Basis of Movement Is Our People: A Disability Justice Primer*.; 2019. <https://www.sinsinvalid.org/disability-justice-primer>
7. Annamma SA, Connor D, Ferri B. Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education*. 2012;16(1):1-31. doi:10.1080/13613324.2012.730511
8. Brown N, Leigh J, eds. *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. UCL Press; 2020. doi:10.2307/j.ctv13xprjr
9. Khavjou OA, Anderson WL, Honeycutt AA, et al. National Health Care Expenditures Associated With Disability. *Med Care*. 2020;58(9):826-832. doi:10.1097/MLR.0000000000001371
10. Nouri Z, Dill MJ, Conrad SS, Moreland CJ, Meeks LM. Estimated Prevalence of US Physicians With Disabilities. *JAMA Netw Open*. 2021;4: e211254. doi:10.1001/jamanetworkopen.2021.1254
11. Swenor BK, Munoz B, Meeks LM. A decade of decline: Grant funding for researchers with disabilities 2008 to 2018. *PLoS One*. 2020;15: e0228686. doi:10.1371/journal.pone.0228686
12. VanPuymbrouck L, Friedman C, Feldner H. Explicit and implicit disability attitudes of healthcare providers. *Rehabil Psychol*. 2020;65(2):101-112. doi:10.1037/rep0000317