#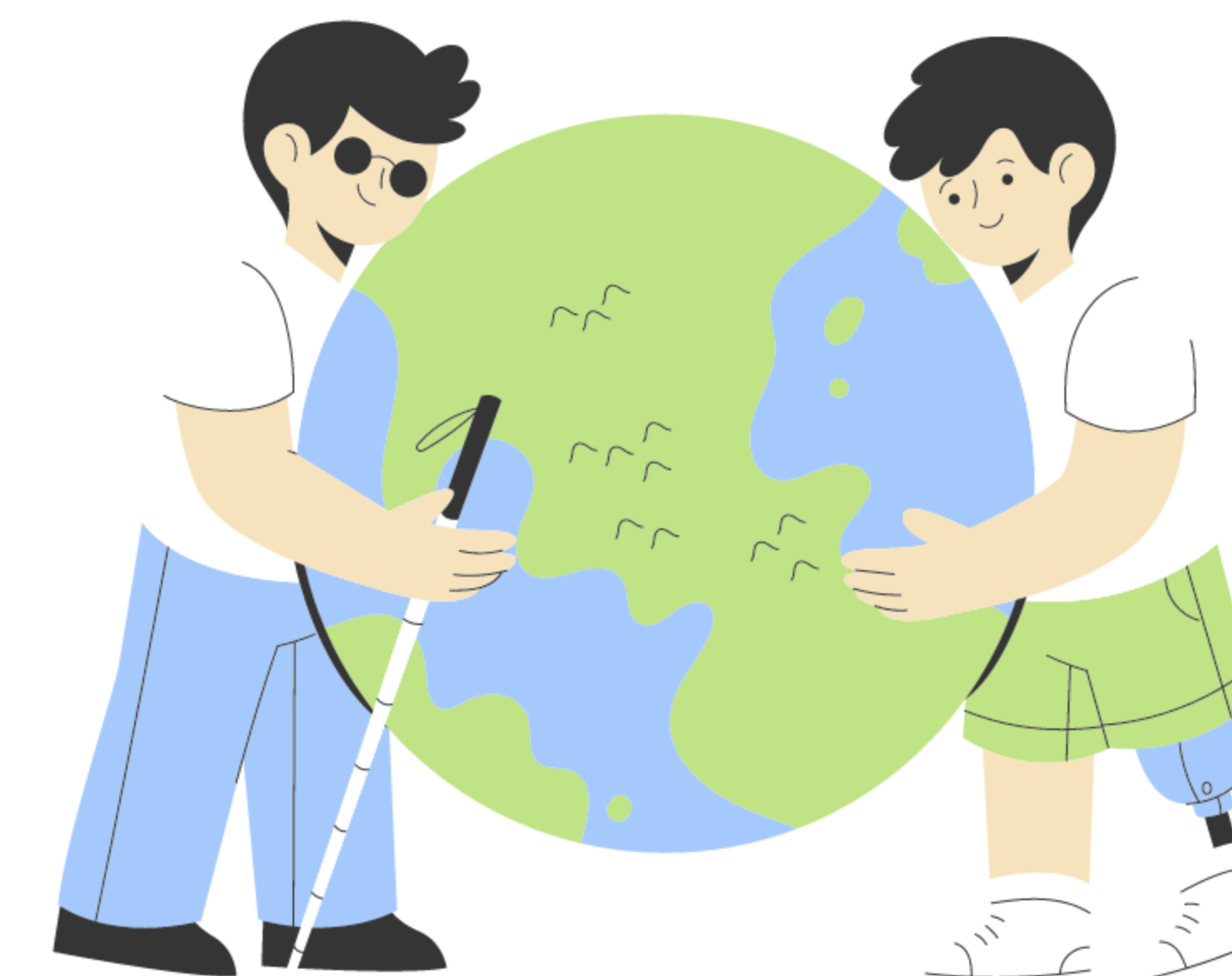 The Institutional Entity: Conceptualizations and Medicalization of Disability Experiences in Northeast and Central Texas

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Introduction

Scholarly review within disability anthropology, the intersectional field between medical anthropology, applied anthropology, and disability studies, has recently become more relevant as the world enters a "post-pandemic" period. However, the pandemic era is quite active; its effects created syndemics, the aggregation of two or more concurrent or sequential epidemics or disease clusters in a population with biological interactions, throughout the globe. As a result, many have questioned their control over their health and societal conceptualizations of disability under institutions of power, especially in historically marginalized communities, such as the disability community, continuing a cycle of systematic violence solidified by policy.

The linguisitic history behind the term "disability"

The social term disability has been used in language to define identity, a state of being, and experiences of those who are deemed as 'other' by an abled-bodied society. In order to understand how disability is considered a social term, we must look at the evolution of the term through language within the 20th century. The term emerged with negative connotations to describe individuals who did not fit societal norms or the biomedical model of health, labeling them as deviants, or social outcasts (Lindholm 2007: 103), to able-bodied society during the beginning of the 20th century. However, the social model of medicine was later implemented and the perception of the word disability began to change into a way for individuals to reclaim the world in a positive perception based on culture, experience, and expression (Andrews 2019:112).

Objective

This research highlights interdisciplinary discourse surrounding disability-related experiences in language, conceptualization, and policy surrounding healthcare within Northeast and Central Texas.

Theoretical Frameworks

Biotypology – The eugenic ideology that categorizes human populations into distinctive types based on phenotypic variables, creating illnesses based on racial categorization (Edu 2023: 5).
Debility - a social phenomenon focusing on the variables that wear down vulnerable populations, leading to widespread disability instead of the before or aftereffects (Garimella 2021: 218).
Embodied self – Conceptual framework on how the constituent parts of the body, mind, soul, self, and more all relate together and how the body experiences health and sickness (Margaret Lock and Scheper-Hughes 1987: 7).
Labeling Theory – The process of assigning people to the category of outsider depends not so much on their innate temperaments but on how they are regarded by society (Lindholm 2007: 300).
Necropolitics – Social policies created by political regimes that determine which lives are worth protecting and not protecting against death and illness, culling the population based on social determinants of health, specifically in the case of COVID-19 (Fonesca and Fleischer 2021: 257).
Sapir–Whorf hypothesis - the social context of language is reciprocally affected by cognition (Andrews 2019).
Social determinants of health - economic stability, physical environment, education, food, community and social context, and accessibility to healthcare.
Ubiquitous ableism – The social process of discrimination and prejudice against individuals with disabilities while the social majority favors non-disabled individuals (Andrews 2019: 452).

Methodology

Methods conducted throughout the research study began in April 2023 with a research proposal to conduct ethnographic observations and literature review surrounding disability studies, law journals, and ethnographic case comparisons to develop interdisciplinary discourse and theory around medical accessibility and policy analysis. Ethnographic observations and discussions regarding perspectives of disability concerning social determinants of healthcare occurred at the Ambassadors of Christ Church throughout several visits to Henderson, TX and Jacksonville, TX between April and December 2023 and the Hippie Hole and students at the University of North Texas in Denton, TX. The objective of these visits was to converse with members of the communities to determine variables that cause barriers in access to healthcare for those coping with the rising cost of living with disabilities. The primary method for collecting data while maintaining the anonymity of participants was a custom survey using the application, Qualtrics. Survey distribution occurred between January 31 and February 25, 2024, with the response of 20 participants on the platforms Instagram, Reddit, Facebook, and LinkedIn. Data aggregation occurred with Qualtrics and Excel, cross-referencing literature reviews on disability studies and anthropological literature.

Limitations

Limitations include limited sample size of twenty participants with a white majority. Further outreach for continuing research includes a wider scope of participants. Conclusions towards racial disparities cannot be made until further inquiry. A couple of outliers emerged in the data with individuals that selected having a disability, but did not identify with the label disabled, indicating that perception may vary among age group.
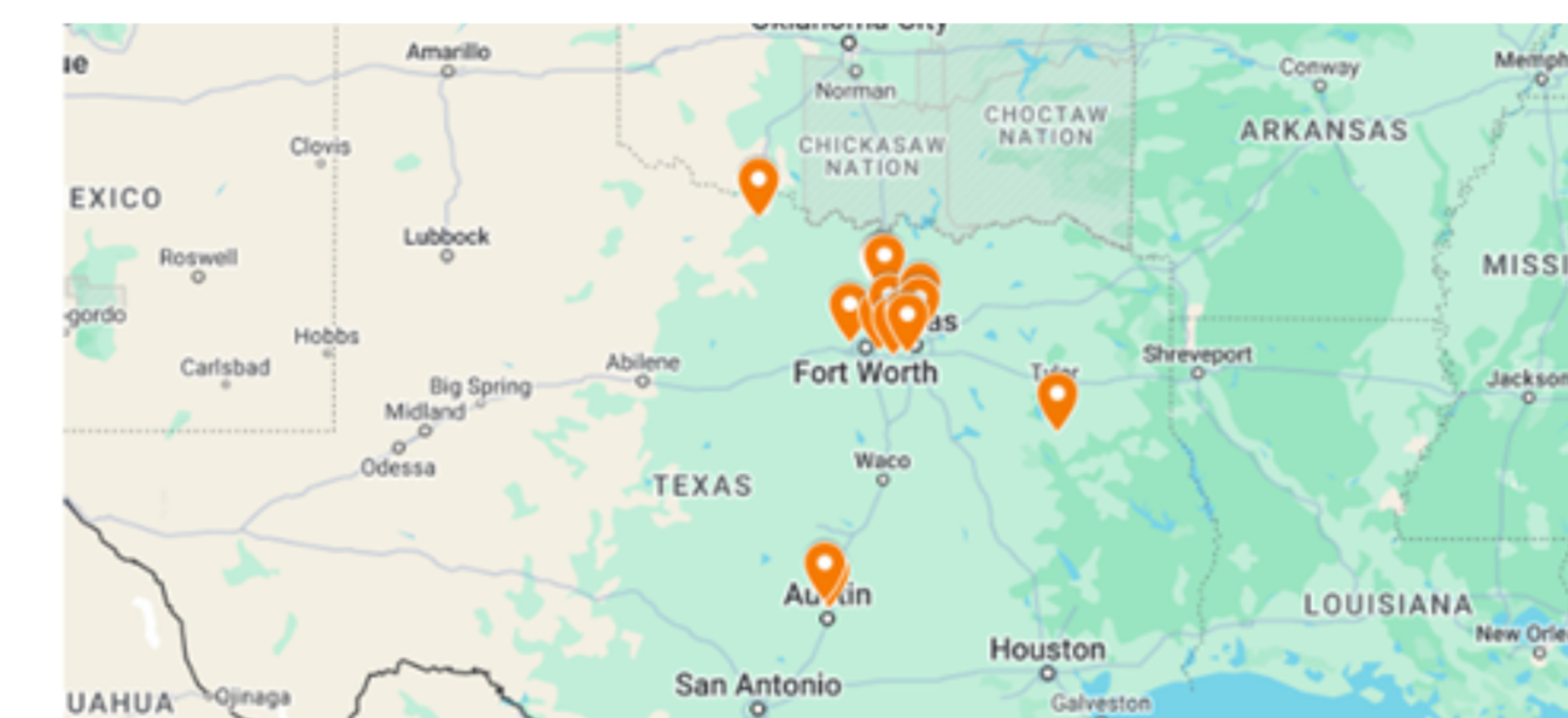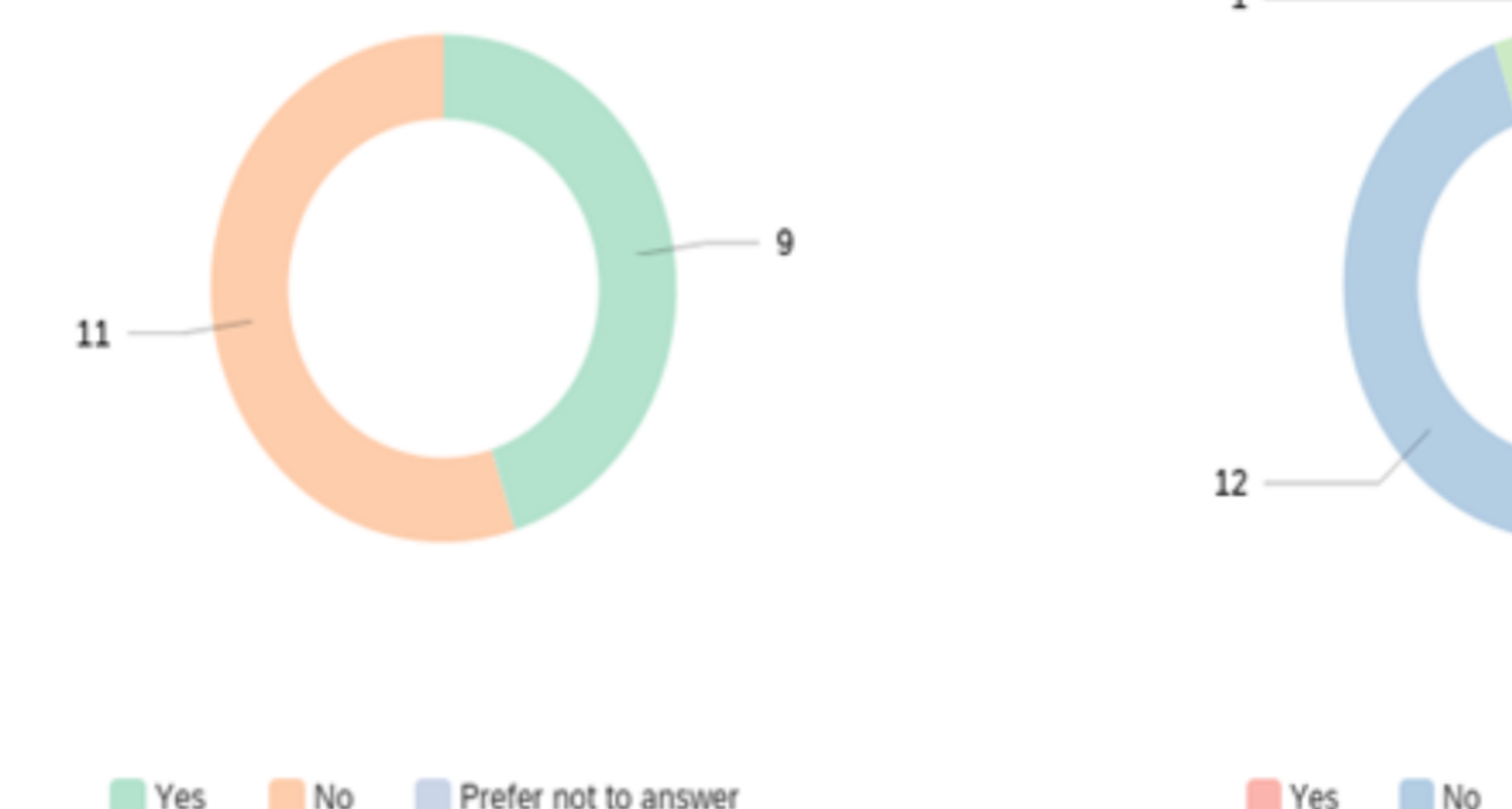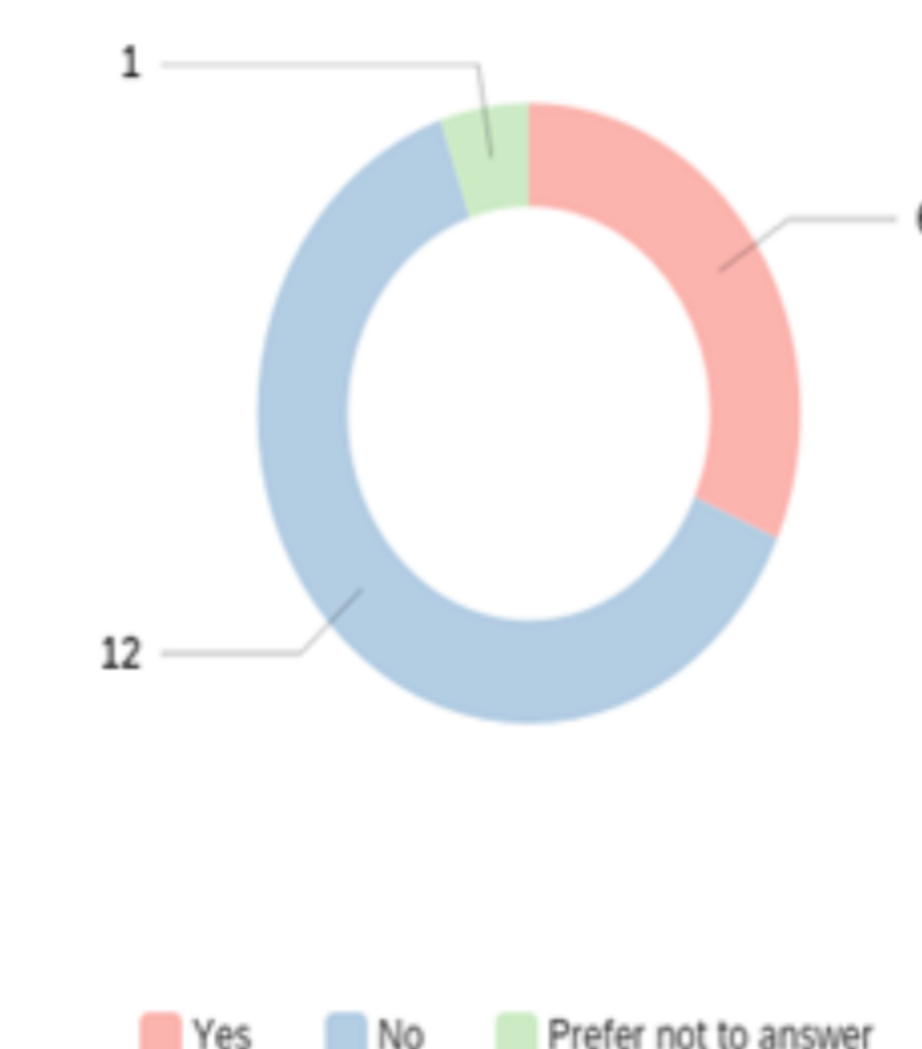
Data Analysis

Figure 1: Participant Response Map

Figure 2: Instances of Medical Discrimination

9 out of 20 participants stated they experienced medical discrimination based on ability status, specifically 45 percent.

Figure 3: Recipients of Supplemental/Social Security Income

6 out of 20 participants indicated being on Supplemental Security Income, 12 did not and 1 did not answer.

Conceptualizations of Disability

One of the reoccurring themes among participants in the survey was the connotation of how the term disabled is used. When asked how they felt about identifying with the term disabled, participants' comfortability with the label was 45% percent, those who were not comfortable were 25% percent, and those who were unsure or depended on the context of its use were 30% percent. Based on the intersection of participants, their descriptions of how they identified with the disabled label and defined the social term of disability in their own cultural and community experiences, the resounding theme of social isolation and limitation further displays the social exclusion of the disability community from everyday society in nuanced interactions. This creates a veil of resiliency that able-bodied society has labeled onto the experiences of those living with disabilities. There is no denying that disability has some biological basis, but it is stigmatization by society that places the label on the human condition they do not consider 'normal' or 'functional.'

"It just means your struggles have labels. Other people have struggles that don't."
"Unable to function 'normally' in society and must adapt."

Medicalization of Disability

Throughout the responses, there is a consistent pattern of unequal treatment and power dynamics between doctors and patients; even though many respondents have answered that they trust clinical medicine, it is conditional when considering the social factors in medicine. Ubiquitous ableism, the social process of discrimination and prejudice against individuals with disabilities while the social majority favors non-disabled individuals (Andrews 2021: 452), is prevalent in medical interactions. The more formal term for doctors taking patients' stories into account in a biomedical model, ignoring the social determinants of health in the process, is known as the "medical gaze." French philosopher Michel Foucault developed the medical gaze phenomenon, conveying "that doctors are doctor-oriented, not patient-oriented, and thus medicine creates an abusive power structure (Misselbrook 2013)." These responses of doctors towards patients with disability in medical institutions are still deeply rooted in colonialist ideology. Comments such as only referring to a patient's depression and neglecting basic testing for issues more profound than the surface level when the patient is conveying their concerns is part of a nuanced process of power, putting the decision of an individual's health in the hands of those who represent the higher power rather than the patients themselves.

"I have a rare disease that some doctors don't believe even exists, it's nearly impossible to treat and barely researched. When I went to the doctor because of a bad flare up, I was giving several uncomfortable and unnecessary diagnostics only for the doctor to say that I must have overexerted myself and to use ace bandages on my ankles and wrists and take Tylenol (this disease attacks various vital parts of my body). He ignored my elevated white blood cell count and blood pressure."

Economic Debility

January 2024 saw an increase in the cost-of-living adjustment for Social Security recipients due to rising costs of living. To further investigate systematic violence against individuals with disabilities, understanding how financial freedom is regulated in accordance with policy is integral. Questions about the cost-of-living adjustment were asked to determine if participants thought it would allow more economic freedom or limit it, and if participants were aware of the adjustment. Among qualitative accounts from SSI recipients, many indicated the SSI adjustment further limited capital:

"My income is still limited, either way."
"I was not aware. I do work with individuals who receive SSI and am skeptical that the adjustment will be sufficient."
" No extra freedom."
"I believe it should be more."

Figure 4: Word Map of Trust in Medical Industry

Key Disability Policy

1935 - Social Security Act
1938 - Fair Labor Standard Act
1954 - Brown vs Board of Education
1965 - Title XIX/Medicaid
1974 - Individuals with Disabilities Education Act
1975 - Developmental Disabilities Assistance and Bill of Rights Act
1990 - Americans with Disabilities Act
2009 - Rosa's Law
2024 Texas Acts – HB54, HB446, SB477, SB1606

Perceptions and Experiences of Disability Concerning Healthcare and Community Survey

Related Literature:
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