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ONE HEALTH, COMMUNITY ENGAGEMENT, AND PRAXIS: SHIFTING THE HEALTH EQUITY PARADIGM

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ONE HEALTH, COMMUNITY ENGAGEMENT, AND PRAXIS: SHIFTING THE HEALTH  
EQUITY PARADIGM

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A capstone project submitted for Graduation with University Honors

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## ABSTRACT

Southern California is commonly known for its diversity, beaches, sunny weather, and active lifestyle. Such representations in popular media paints this region as one beaming with health and well-being. However, the dreamy California life is well out of reach for many living in the inland areas. The Inland Empire (IE) is a prime example of the region's disproportionate health disparities. There is a clear disconnect between the health needs of IE residents and the health resources to which they have access. Health is a cornerstone of life; a basic need that has been turned into a commodity via exorbitant healthcare and insurance costs, privatized health knowledge, lack of representation in health research and policy, exploitative labor practices, ecological degradation, as well as interpersonal and structural discrimination. Such health disparities are a startling reminder of the role structural inequity plays in determining who dies, who survives, and who thrives. Additionally, the roots of observed health disparities lie in the nation's treatment of and attitude towards indigenous populations and land, people of color, queer communities, women, and others deemed inferior by patriarchal social norms. The role of the current study is to employ a One Health lens—the understanding that human, animal, and environmental health are deeply intertwined—to center the lived experiences of health inequity in the IE. Through a review of existing literature, community interviews, and an ArcGIS webpage, this project is intended to serve as a contribution to the development of sustainable, community-centered strategies for achieving health equity.

**Keywords:** One Health, Health Disparities, Health Equity, Health Equity Paradigm; Community Engagement, Praxis, Interpersonal Discrimination, Structural Discrimination, Necropolitics, Human Rights; Ecological Grief, Heteronormativity, Western Biomedicine; Science Communication, Community-Based Participatory Research

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## TABLE OF CONTENTS

	Page
SECTION	
LIST OF FIGURES.....	7
I. INTRODUCTION.....	12
II. METHODOLOGY.....	12
III. LITERATURE REVIEW.....	13
1. Health Disparities.....	13
Social Determinants of Health.....	13
Interconnectedness of Health and Social Justice.....	14
Communication Infrastructure Theory and Health Disparities.....	14
2. Social Psychology.....	16
Biases in Clinical Care.....	16
Overarching Attitudes Towards the “Other”.....	17
Compounded Health Disparities.....	18
3. Medical Anthropology.....	19
Individual and Micro-Level Scope.....	20
Larger Social Formations.....	21
The Environment.....	22
Epigenetics.....	24
Ecological Systems Theory.....	24
The Microsystem.....	24
The Mesosystem.....	25

The Exosystem.....	25
The Macrosystem.....	26
The Impact of Healthcare Systemic Interrelationships.....	27
Humans and Other Species.....	28
Cultural Norms and Social Institutions.....	29
Micro and Macro Politics.....	31
Forces of Globalization.....	32
Anthropological Research Methods.....	33
Research as Resistance.....	33
IV. ETHNOGRAPHY.....	34
Lived Experiences of Health Disparities.....	34
Project 1: The Inland Empire.....	36
Community Interviews.....	36
Findings.....	37
Ideas for Change.....	40
Project 2: The Salton Sea.....	52
Story Maps.....	54
Project 3: Overlapping Inequities.....	54
QTPOC Health.....	54
Community Voices.....	50
Disability Advocacy.....	57
Community Voices.....	61
Disability Rights.....	61

V. DISCUSSION AND FUTURE DIRECTIONS.....	64
REFERENCES.....	67
APPENDICES.....	76

## LIST OF FIGURES

	Page
<b>Figure 1:</b> Dynamic relationship of SES and health across generations.(Chen et al., 2016).....	21
<b>Figure 2:</b> Framework showing putative causal pathways linking climate change and mental health (Berry et al., 2010).....	23
<b>Figure 3:</b> A multitier framework for analyzing Socio-Ecological Systems SES (Ostrom, 2007, Copyright (2007) National Academy of Sciences, U.S.A.).....	27
<b>Figure 4:</b> Power in CBPR conceptual model (Adapted from Wallerstein et al. (2008) and Wallerstein et al. (2018).).....	32



## INTRODUCTION

*“Access to healthcare has become part of today's American Dream. Research has found that the higher your income, the better your health, on average. As a result, income inequality has led to healthcare inequality.”*

*-Kimberly Amadeo, (2022)*

Systemic injustice is an undeniable contributor to health disparities among socially marginalized communities in the United States. To gain a thorough understanding of the problems at hand to develop and implement sustainable, community led and supported plans for collective healing and equitable access to well-being and prosperity, it is necessary to dissect the array of influences, patterns, and perpetrators that enable and exacerbate the conditions of precarity that lead to inequitable life outcomes. With this in mind, I set out to understand how systemic injustice is involved in health disparities, and what institutional mechanisms drive this process.

So, what is actually happening in our country? Why must we work tirelessly to attain a livelihood that does not sustain us; that does not support us in our times of need? Amid this climax of global health upheaval, many of us find ourselves flooded with waves of anxiety, despair, and unease. Everything we know is in question, leaving us “Naked and Afraid” as we are asked to continue producing, unphased by the desecration of our land, consequences of a pandemic, and political nightmare of the past several years. When our structures of power crumble, it is upon us to recognize our chance to act. The problem is, as a society, we have been subjectified by power dynamics within the American system. We have been marginalized, and conditioned to adopt an “us versus them” mentality, fueled by institutional racism intended to stratify those who do not benefit from the system as it exists. Separated from our natural communities via imposed categorization in a culture of canonical obsession, our inherent

strengths have been introduced and overexplained to us as weaknesses. Soft power, compassion, emotional intelligence, pleasure; all devalued and scoffed at by neocapitalist demagogues and yet, all necessary for individual and societal healing. Due to the social precarity brought about by American colonialism and ostracization of anyone failing to adhere to socially approved belief systems and ways of life, our collective power has been scattered.

We, as a people, have been denied human rights that were introduced into international treaties in 1944, but rejected by the US congress and ignored in the creation of law. Healthcare, nutrition, shelter, agency. These are not luxuries, but basic needs denied to many living in the United States. The US's role in colonization and slavery since its birth ripples the waters of peace internationally and here at home. People in the United States do not have a legal right to adequate healthcare, food supply, shelter, or the ability to make a living wage in this system of neocolonial capitalism. This issue is not new, but one that roots deeply into the fibers of American history, telling a tale often left out of history books and state-recorded knowledge.

Historically, populations marginalized by the system of power are excluded from conversations on how to address the issues that they are facing. Health professionals, researchers, and policy makers often assume an air of superiority, treating their patients and communities as less than because of preconceived notions of entitlement that come from "making it" in the American system. Why do people in power get to decide where resources are extracted from and where they are distributed? How is it that the same people who are destroying our world are the ones living comfortably while their subjects fight to survive? This is simply not sustainable. Imbalance of power is unstable in nature and bound to react when placed under pressure. The state of our world, riddled with war, disease, poverty, and violence is the direct result of neocolonial capitalism. The mechanisms of the system in place, domestically and globally, are

common threads of processes designed to uphold structures of power. The resulting dynamics work to disenfranchise communities who do not fit into the dominant ideals of the ruling class and undermine efforts of resistance by writing them off as heresy. This disregard for voices besides those of the ruling class is intentional, as it allows the narration of history to remain in favor of their control. Necropolitics is the use of social and political power to dictate how some people may live and how some must die (Mbembe, 2003). The American system employs necropolitics in its treatment of non-dominant groups in many aspects of life, from institutional racism and discrimination, to degradation of indigenous lands; from exploitative labor practices to insufficient healthcare. Slow violence is the resulting harms of systemic discrimination which, “constitute cultural trauma and shape health, well-being, academic performance, government participation, community membership, and physical space,” (Kramer & Remster, 2022). To understand the intention of this project, it is necessary to first consider the nature of the system in that it utilizes necropolitical slow violence to maintain its power.

*“But under what practical conditions is the right to kill, to allow to live, or to expose to death exercised? Who is the subject of this right? What does the implementation of such a right tell us about the person who is thus put to death and about the relation of enmity that sets that person against his or her murderer? Is the notion of biopower<sup>1</sup> sufficient to account for the contemporary ways in which the political, under the guise of war, of resistance, or of the fight against terror, makes the murder of the enemy its primary and absolute objective? War, after all, is as much a means of achieving sovereignty as a way of exercising the right to kill. Imagining politics as a form of war, we must ask: What place is given to life, death, and the human body (in particular the wounded or slain body)? How are they inscribed in the order of power?” -Achille Mbembe (2003)*

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<sup>1</sup> Biopower: that domain of life over which power has taken control (Mbembe, 2003)

How is it that a system gains this type of power? How does it maintain the conditions necessary to remain in control? History would suggest that it does so by ensuring that its institutions abide by standards that uplift conformers and punish dissidents; by acting with a “shoot first, ask questions later,” mentality; by withholding financial support for health, education, and stability to fund militarized-police forces and satiate the wealthy. This project is meant to demystify the actors behind these standards and incite discussion on American Necropolitics and the role of this system on the livelihoods of the people it marginalizes, with specific emphasis on lived experiences within the US healthcare system. To do this, I dive deeper into the consequences of American Colonialism on health through an ethnography of lived health experiences in Inland Southern California. My goal is to highlight the need for further research on the underlying mechanisms of health disparities, and open a line of communication between researchers, healthcare professionals, and community members to engage in dialogue on the subject.

### **Guiding Questions**

1. What is known about the roots and implications of Health Disparities in the United States?
2. What are the main barriers to accessing healthcare?
3. Who benefits from the current healthcare system in the US; why does it continue to exist in its current form?
4. How are individuals’ lives impacted by health disparities in the Inland Empire of Southern California?
5. What plans for alleviating health disparities are already in motion?

## METHODOLOGY

My approach to understanding health disparities involved a three-year long field-project within the inland community of southern California. This project in which I recorded my observations from my time with other students, coworkers, friends, and family members prompted me to learn more about common health challenges and barriers to accessing care that people face. What I noticed time and time again was the clear, interconnected relationship between socioeconomic status and social identity and access to quality healthcare. The more I learned from the communities I was a part of, the more cognizant I became of the structural inequity present in our society. I began to question the reality that I was living in, wondering how such an affluent nation could possibly have such extreme health inequity. This question stuck with me, in the back of my mind, day in and day out. I knew that there was more to the story than meets the eye, and I became determined to figure out why health disparities exist. What I found, was not exactly shocking, but bone-chilling nonetheless. The deeper I searched into the literature surrounding health disparities, the faster the façade of American “liberty and justice” faded away. Seeing the exposed mechanisms of American neocolonialism opened my eyes to the extent to which structural inequity shapes our day-to-day lives. I decided to devote my studies to understanding not only what health disparities are, but what conditions are necessary to restore health equity. These questions motivated me to explore literature on forces that have led to the existing climate of health and healthcare, as well as recorded strategies for combatting health disparities. This review helped me develop questions to ask members of the community, both to understand more about lived experiences of health disparities, as well as to compile a community narrative addressing the issues within our system. My methods integrate strategies from the fields of social psychology and medical anthropology aimed at conducting

community-based participatory research to facilitate dialogue and bring attention to the reality of life in the US for those without adequate healthcare access.

## LITERATURE REVIEW

### **Part 1: Health Disparities**

#### **Social Determinants of Health**

In the modern age of attention to health equity, much has been revealed about the cyclical nature of poor health outcomes among marginalized communities. Social Determinants are defined by the Center for Disease Control as “conditions in the places where people work and play that affect a wide range of health and quality-of-life risks and outcomes,” (CDC, 2022). In a two-year long “science visioning process” for health disparities, the National Institutes on Minority Health put together a series of workshops to identify potential directions for research on the subject. Through the process, Palmer et al. found that social determinants of health were a central theme among these workshops, and that research was needed on the “upstream” social determinants of health. Upstream research on these determinants found that “Racism and discrimination have not only shaped economic and social policies in the United States but also directly influenced the lived experiences of racial and ethnic minorities,” (Palmer et al., 2019). This argument is supported in the book *Unequal Treatment*, which examines “how disparities in treatment may arise in healthcare systems,” and the different aspects of clinical encounters that may contribute to this reality. While this piece outlines barriers and potential combative strategies, the committee was held back from creating a more comprehensive framework for “disentangling the many influences on the process, structure, and outcomes of care” due to a lack of support from federal and private sources, (Smedley et al., 2003).

## **Interconnectedness of Health and Social Justice**

This situation speaks to the deep interconnectedness of health disparities with other issues of injustice not explicitly related to health. The relationship between health literacy, health, and the disproportionate burden of health disparities on disenfranchised populations reflects “serious and fundamental forms of social injustice outside the healthcare context that interact with and further confound clinical care,” (Schillinger, 2007). This process reflects the presence of the Inverse Care Law, which states that “the availability and quality of good medical care tends to vary inversely with need among the populations served,” (Tudor-Hart, 1971). The history of this issue, dating back to 1971, reveals that concern over disproportionate access to care is not novel, but something that has been regarded as insignificant by primary policy makers given the lack of resolution of the matter. This can be partially explained by efforts to address health disparities that were missing critical components of the larger picture, such as the bi-directional, cyclical nature of health inequity, the US system of marginalization, and how “multifactorial causal pathways” are influenced by upstream social determinants of health and lead to downstream health disparities, (Duran & Pérez-Stable, 2019).

## **Communication Infrastructure Theory and Health Disparities**

The communication infrastructure theory is a form of ecological approach that observes how medical and health disparities can be addressed and potentially reduced. It has two components; they are the storytelling system and the communication action context. According to the theory, people’s connections to a multilevel storytelling system, ergo describing medical and health experiences and outcomes, are either enabled or hindered by the communication environment and communication action context (Wilkin, 2013). To exemplify, and in relay to healthcare disparities, Wilkin (2013), focuses on the relationship between the cohesive

connections of the neighborhood storytelling network and health and treatment outcomes.

Additionally, healthcare disparities are more aggravated by neighborhood-level influences. Low-income communities are oftentimes and too frequently deprived of healthy food options and education regarding adequate diet and exercise, preventative care, and access to extracurricular activities and resources such as gymnasiums or public park equipment.

Furthermore, existing research on the communication infrastructure theory has been an increasing variable in studies regarding community-level health disparities, geographically and ethnically based (Wilkin, 2013). Wilkin (2013) further presses that the communication infrastructure theory is considered to be the basic communication method of a community. In the context of health advocacy, health communications include macro-level storytellers such as government health officials and organizations, cultural and societal institutions, and drug and food manufacturers. Campaigns such as VERB employ their efforts at the mezzo-level scale through outreach that include community programs (Berkowitz et al., 2008). At the micro-level, interpersonal relationships and networks that include family, friends, colleagues and coworkers and religious leaders (Wilkin, 2013) can impact how individuals receive information and content, which then influences decisions regarding healthcare and lifestyle choices.

The presuppositions of research surrounding the theory are that location and ethnicity matter. Individuals of the same ethnic background and who live in different communities may connect and relate differently to various storytelling systems. However, it is also possible that individuals of different ethnic backgrounds who live in the same geographic community may connect and relate to different storytellers (Wilkin, 2013). Thus, a completely integrated storytelling network should be diversely structured in order to address the concerns and interests of all communities from different socioeconomic and ethnically diverse backgrounds. It is



crucial that health communications scholars are able to recognize the need for identifying the socioecological variables that influence how communities are adversely impacted by how conversations about health are shared.

## **Part 2: Social Psychology**

### **Biases in Clinical Care**

Health disparities are a multidimensional issue that arise from systemic prejudice, bias, discrimination, and marginalization. This section of the literature review explores forces that have shaped the existing social climate regarding health as well as the interrelatedness within the human condition that allows these systemic issues to trickle into health research and clinical practice. Health outcomes among ethnic minority groups in the US are significantly poorer than among white Americans, which can be attributed to structural factors of the US system as well as racially based biases by healthcare providers. In many instances, biases operate in “unexamined but systematic ways to adversely affect medical decision-making, clinical interactions, and the responsiveness of patients,” (Dovidio & Fiske, 2012). In the healthcare setting, it has been found that “warmth” and “competence” are two characteristics which are highly valued by health practitioners, and when patients are perceived as low in either of these, they “elicit more contempt and disgust,” than other groups. Given the relationship between emotions and behavior—in which emotions predict behavior—Dovidio and Fiske (2012) describe how these emotions of contempt and disgust predict “a vicious combination of discriminatory behavior: both passive harm (neglect, demean), and active harm (attack, fight). This pattern of biased emotion and discriminatory behavior is harmful on many levels, as it not only makes care less effective, but also reduces the willingness of patients to adhere to treatment plans and return for follow-up visits. Subject to individual level discrimination and institutional racism, individuals

from racial/ethnic minority backgrounds are placed in a position of “double jeopardy,” where they are forced to endure dismissal and aggression from healthcare providers as well as a variety of adverse health outcomes including “higher mortality; lower use of cancer screening; elevated blood pressure; higher levels of C-reactive protein; substance use; mental and physical health including mood, anxiety, and psychiatric disorders; increased depressive symptoms; weight gain; high body mass index; and smoking,” (Shavers et al., 2012). Although physicians are trained to inhibit direct explicit bias in their provision of care, “implicit bias, both independently and in combination with explicit attitudes,” shape the dynamics of patients and providers and ultimately result in poor treatment of patients who elicit negative bias from their care providers simply from their existence (Dovidio et al., 2016).

### **Overarching Attitudes Towards the “Other”**

Aside from clinical care, overarching attitudes towards ethnic/racial minority groups frequently emanate from a “zero-sum” perspective, in which members of the “establishment” group—White Anglo-Saxon Protestants—feel that they “lose” if a non-dominant group “wins,” (Moody et al., 2021). This coincides with the seemingly intentional structure of the US healthcare system which systematically discriminates against non-dominant groups and refuses to undertake changes that may upset the traditional social hierarchy and its related privileges. In 1944, President Roosevelt introduced a proposal for a second Bill of Rights, which included entitlement to “adequate medical care and the opportunity to achieve and enjoy good health,” among other basic needs, but it was immediately shot down by the US Congress, who “denied that the government could do anything to protect the citizen in his right to work and his right to live,” (Sunstein, 2004). Though rejected in the United States, this Bill of Rights was adopted into international Human Rights treaties and held as precedent for nations around the world. So why

not in the United States? Literature suggests that this disregard for the importance of adequate healthcare in the US can be attributed partially to an unwillingness of the population to vote for the implementation of an equitable healthcare system due to financial costs associated with increased taxes and an excessively high value placed on individual liberty that would, in the eyes of some, be compromised with universal healthcare (Flannigan, 2017). Furthermore, some arguments against universal healthcare include fears of general system inefficiency, such as “wait-times for patients and a hampering of medical entrepreneurship and innovation,” though the only people who do not already experience these issues are those favored by the existing system, (Zieff et al., 2020). While further research is needed to uncover specific instances in which efforts to create a universal healthcare system were shut down, the general sentiment surrounding the issue is that white Americans in general are unwilling or unable to look beyond their own needs, individual freedoms, and financial growth to acknowledge the needs of the populations that are sacrificed to keep the status quo alive. In the context of health disparities, these sentiments reveal racist, heteronormative undertones that perpetuate the system built on inequitable foundations and overlook the impact of this system on the lives of people of color living in the United States.

### **Compounded Health Disparities**

As demonstrated by the US government’s history of disregard for equitable health conditions, attitudes of racism and superiority are characteristic of and even encouraged by those in positions of power. Given this reality, it is no wonder that ethnic/racial discrimination is at the center of the American healthcare system. Psychologically, the impact of this prejudice serves to compound the stress associated with accessing healthcare for minority groups. When layered with other forms of “alternative” identity, such as sexuality or religion that deviates from

dominant norms, individuals face further discrimination in healthcare settings and experience a “hypermarginalization from quality care,” and “greater vulnerability to poor health care,” due to their ethnoracial status and minoritized ways of life (Sewell & Pingel, 2018). Social Psychology is crucial to understanding the formation of the healthcare system and the ways in which cognitive and implicit bias, prejudice, discrimination, and marginalization shape access to and quality of care for individuals who do not meet the standards of what it means to be “a hard-working American,” as well as the impact of this burden on the overall health and well-being of these individuals.

### **Part 3: Medical Anthropology**

Medical anthropology is a field that draws upon social, cultural, biological, and linguistic anthropology. This field of study allows for better ways to explore and understand those factors which influence health and well-being, the experience and distribution of illness, the prevention and treatment of sickness, healing processes, the social relations of therapy management, and the cultural importance and utilization of pluralistic medical systems. Medical anthropology examines how the health of individuals and communities, larger social formations, and the environment, are affected by the interrelationships between: (1) humans and other species; (2) cultural norms and social institutions; (3) micro, mezzo, and macro political systems; (4) the forces of globalization; and (5) the overall impacts and effects of each relationship on local worlds (Society for Medical Anthropology). This project explores and adopts methods employed in medical anthropology research to observe how the health of individuals and communities, larger social groups, and the environment are affected by the interrelationships between cultural norms and customs, social constructs and institutions, the government, and the vast forces of

globalization. These interrelationships can also be explored through the ecological systems theory.

### **Individual and Micro-Level Scope**

Poverty and health disparities in the United States are social issues that have yet to be resolved. An individual's socioeconomic status, ethnicity, and cultural background continue to be prevalent and omnipresent in determining the outcomes of one's health and quality of life. Cheng et al. (2016), highlight how health issues among low socioeconomic families are transferred heritably from one generation to the next. Their study embarks on a framework review to understand intergenerational transmissions of health disparities. They then combine those findings with research pertaining to programs and policies and current leading methodologies and theoretical frameworks in practice that are dedicated to poverty. This component is the 2-generation approach. The authors then imply that research approach centered on intergenerational health disparities should include three generations of families to observe for implications and results (Cheng et al., 2016). Including three familial generations posits broader insight and learning opportunities to assess how life course trajectories, policies, culture, and other factors impact families' biological, behavioral, social, and environmental aspects of their lives (Cheng et al., 2016).

The theoretical frameworks that the authors of the study employed are the Developmental Origins and Adult Disease, Life Course Health Development, Allostatic Load, Intervention Approach (2-generation), and 3-generation. Through the integration of the frameworks and observing three generations of epigenetics being expressed, Cheng et al.'s (2016), research indicates that social disadvantages are some of the greatest obstacles that low-income families are dealt with. Such disadvantages implicate these individuals as they are more likely to

experience cognitive deficits, difficulties with emotional regulation, trouble with controlling maladaptive and social behaviors, low outcomes in academic performance and achievement, and poor social functioning (Cheng et al., 2016). These implications and risks can be significantly decreased by promoting and implementing healthy and positive behaviors by providing substantial psychoeducation, preventative healthcare, advocating for public welfare policies and extending more community-based programs in neighborhoods that need it most.

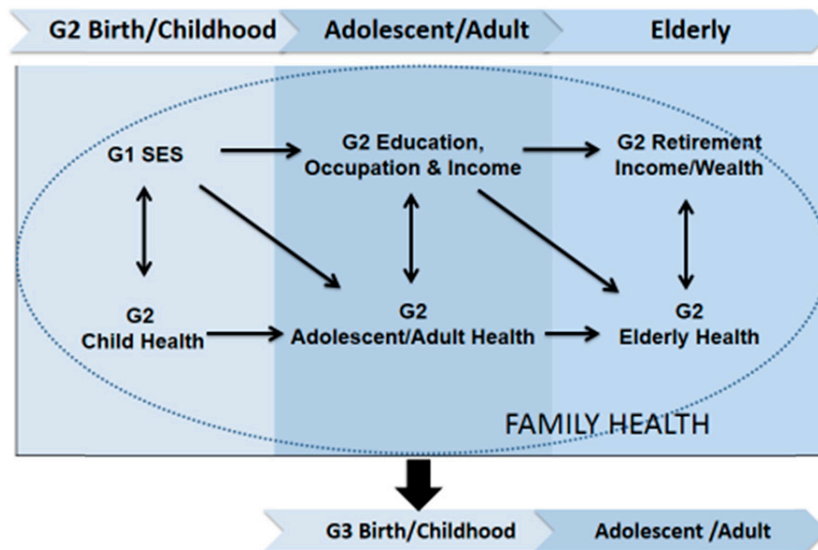


Fig. 1: Dynamic relationship of SES and health across generations. G1: generation 1, parents; G2: generation 2, child; G3 generation 3, future offspring. (Cheng et al., 2016).

### Larger Social Formations

Public policy and government legislation have demonstrated to create and uphold obstacles for low socioeconomic communities. These obstacles have also been unfair to minority groups, and other diverse ethnic groups. Anders et al. (2022) explore the link between racialized economic segregation and health disparities in the United States, which they operationalized with the Index of Concentration at the Extremes. Ultimately, their metanalysis found that racialized economic segregations have a strong effect on the severe risk of developing negative health outcomes across ethnic minority and low-income populations. The research implies that

formations of residential segregation in multidimensional sectors across ethnic minority groups, the likelihood of experiencing poverty increases, and are correlated to also experiencing susceptibility to disease, illness, and poor health (Anders et al., 2022). Public health and efforts exerted toward policy work, healthcare access, and advocacy for health equity can also be met with environmental challenges such as the risks and fear of global climate change and the legislation in place for them.

### **The Environment**

It is important to take into account the effects that global climate change and localized pollutions have on individuals of low-income and low socioeconomic status. Exposure to environmental pollution and toxicities negatively impact the health and well-being of low socioeconomic communities (Do et al., 2021). To exemplify, Do et al.'s study (2021), examined the severity of air pollution in Inland Southern California. Their pilot study stresses the variability in community-scale exposure amongst a socioeconomically diverse air basin that is San Bernardino, California. Their results illustrated the greater and variably exposure of air pollution exposure lies on the majority region of where low socioeconomic individuals reside in San Bernardino. Individuals of higher socioeconomic status primarily reside above the foothills and along the San Bernardino Mountains basin.

Poor environmental conditions and a declination of stability of the global climate, elicits harm amongst ethnic minorities and low socioeconomic populations. According to Berry et al. (2010), the poor quality of ecological and environmental health has adverse effects on the overall health of individuals, which includes their psychological and mental health as well. Through an extensive literature review, the findings reveal that climate change displays a direct effect on mental health along with the exposure to traumatic experiences. However, it may affect mental

health indirectly by affecting physical health and community well-being (Berry et al., 2010). At the mezzo and community level, well-being is a “sub-process” by which climate change manipulates the physical environment and as a result damages social environments. Hence, more vulnerable individuals and groups such as ethnic minorities, low-income communities, and people with a high predisposition of medical conditions who live in the center region of the air basin are exposed most to pollution and toxins in comparison to “healthier” individuals who reside uphill along the mountain ridges.

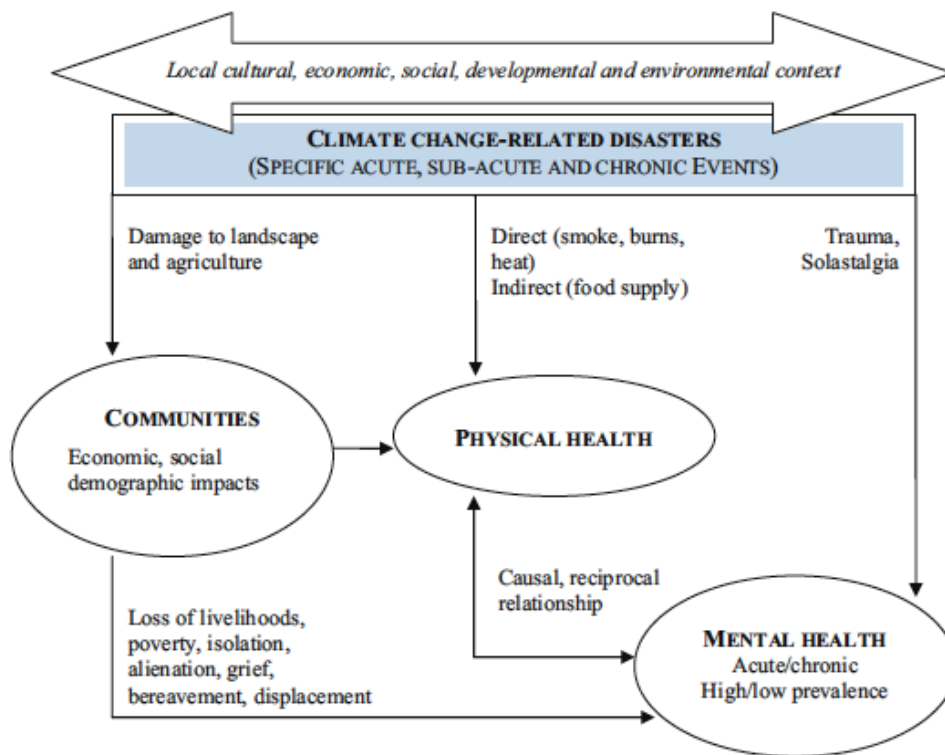


Fig 2: Framework showing putative causal pathways linking climate change and mental health (Berry et al., 2010).



## **Epigenetics**

According to the Centers for Disease Control and Prevention, epigenetics can have a positive or negative impact on one's health and susceptibility to illness and diseases through DNA methylation. Epigenetics conveys how human behavior and an individual's environments can modify the ways in which genes are expressed and encoded in DNA. Despite being attributed to DNA, epigenetics is malleable and reversible, and it does not actually change DNA sequencing. Rather, it impacts how the body functions and how it reads the DNA sequences (Office of Science, Office of Genomics and Precision Public Health, 2020, August 4). Thus, ongoing health disparities and inequitable access to healthcare and preventative treatment can adversely impact the likelihood of susceptibility to diseases and illnesses, passing unfavorable genes that increases predisposed medical conditions. The interrelationship between epigenetics and health disparities can be increasingly explained and observed with renowned psychologist's Urie Bronfenbrenner's ecological systems theory framework.

## **Ecological Systems Theory**

Bronfenbrenner's Ecological Systems Theory (1989) portrays how an individuals' social environments influence and impact their biopsychosocial development, behaviors, and relationships within those systems. His theoretical framework includes five domains being the microsystem, the mesosystem, the exosystem, and the macrosystem (Hertler et al., 2018). These domains are a structured hierarchy as each serves a distinct role in the biopsychosocial development at the individualistic scope.

## **The Microsystem**

The microsystem is the first or foundational domain in the ecological systems theoretical framework. It is comprised of the social structures and primary relationships of an individual

such as the parent-child relationship, sibling bonds, social dynamics at school, relationships within childcare environments, interactions with others in their neighborhood and local community and so forth. Generations of families experience various issues of intergenerational trauma and conditions due to the existing health disparities (Cheng et al., 2016).

### **The Mesosystem**

The mesosystem is the following domain in the framework. Within this component, the relationships and social dynamics of the household and community structures such as schools and childcare environments intersect with one another. These interrelationships impact the psychosocial development of an individual and influence how they engage with others and interact with their environments. During this period of development and within this domain, individuals are able to examine more clearly how health disparities may play a role in their families' susceptibilities to certain medical conditions or those that are common within their community and environments (Breheny & Stephens, 2008).

### **The Exosystem**

This domain consists of the larger social structures which interacts with both the micro- and mesosystems. One's socioeconomic status, parents' employment, community-based resources, community, and school-based programs (which may or may not be government funded or assisted), and access to resources are observed in the exosystem. Socioeconomic disadvantages are adversities that low-income, and minorities encounter and unfortunately it is also cyclical across generations (Breheny & Stephens, 2008). Underrepresented groups and communities appear to be "invisible" to policy makers and governments.

## **The Macrosystem**

The macrosystem is the outermost domain in the Bronfenbrenner's model. Individuals are impacted by local and national governments, cultural values, and norms, and how these factors also penetrate their micro-, meso-, and exosystems. Essentially, the factors in the macrosystem can be observed through a medical anthropology lens as the concerns of health disparities and the limited access and minimal care that minority and marginalized groups face. High-risk individuals and families who face and endure health and treatment disparities and lack preventative care more likely to transcend similar conditions and health related challenges to the next generation if the cycles are not broken (Cheng et al., 2016).

Healthcare disparities have been a subject of concern and injustice for decades, if not longer. Since the twentieth century, research has been conducted to examine patterns and constructs pertaining to anthropology, biology, psychiatry, family systems, epistemology, and linguistics. Bateson and Donaldson (1991) were two of several researchers who dedicated their resources and made contributions to medical anthropology in attempt to better understand the flaws in the healthcare system to improve and enhance the experience of mankind and nature. Integrating Bateson's work and Bronfenbrenner's ecological systems theory (1989) into medical anthropology, current researchers and clinicians can better consider how the current states of economy, local and national governments, and cultural norms shape individual schemas and epigenetic traits (Evans et al., 2021).

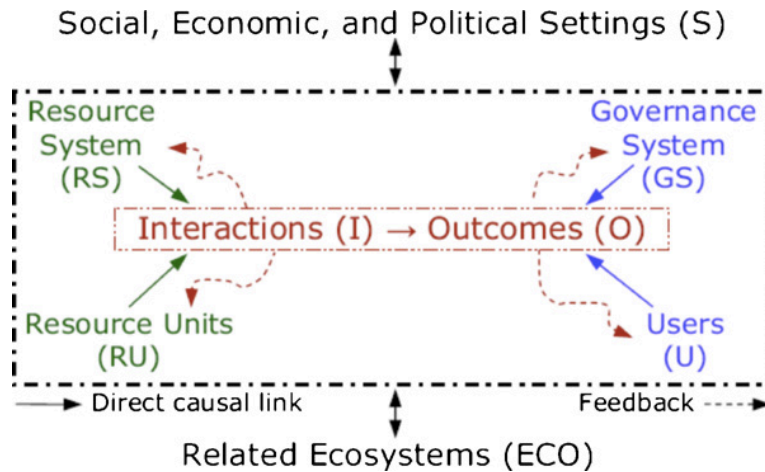


Fig. 3: A multitier framework for analyzing Socio-Ecological Systems SES

(Ostrom, 2007, Copyright (2007) National Academy of Sciences, U.S.A.).

### The Impact of Healthcare Systemic Interrelationships

Human behavior is complex, and it is influenced by the environment, social aspects, intra- and interpersonal relationships, and the interrelationships of each variable. Research posits two interrelated issues that are harming humanity. Those adversities are the health and well-being of low-income populations and the conditional state of the natural environment (Brymer et al., 2019). Researchers stress the importance of expanding on research pertaining to the relationships between humanity and the natural environments. There is an ongoing crucial necessity for interdisciplinary collaborative efforts and execution of developing aids to improve the declining conditions of the natural environments on which low-income and low socioeconomic populations prominently reside. Studies such as that of Brymer et al. (2019), press for the unity of human and planetary health is a universal matter and concern. The evidence presented by research is strong – the well-being of populations to come and the state of the Earth, including global climate change is dependent on a cross sector commitment of political figures and organizations (Brymer et al., 2019).

*Humans and other species.* The impacts of climate change are becoming more and more visible. These adverse impacts are also increasingly creating additional challenges for vulnerable populations, such as those living in coastal ecosystems (Zinsstag et al., 2011). The global climate is changing rapidly the changes are manifesting differently across ecosystems and environments. In that there is an unextractable interconnection of humans, animals (as pets), livestock, and wildlife. Zinsstag et al. (2011), briefly discuss the vast history of integrative thinking on human and animal health. They also review “one medicine” and “ecosystem approaches to health” among the theoretical landscape of contrasting and neighboring approaches, and they explore the various strategies of systemic approaches to maintaining and protecting the health of animals and humans as a whole.

“One medicine” is depicted as to the complete and whole recognition of the interactions within and between humans, animals, nutrition, livelihood, and health (Zinsstag et al., 2011). They further argue that there is no difference in the paradigm of human and veterinary medicine, but rather the paradigm is an extension of notions of relative medicine. Researchers and physicians should increase collaborative efforts to refrain from the notion of “other one medicine,” and make further progress toward the emergence of integrating the overall health and well-being of all species. This approach posits for a notion and conceptualization of viewing medicine and livelihood of all living beings as “one health.” It is described as the combination of concepts including “ecosystem health” and “one medicine” that encompasses the entire environment, all wildlife, and environmental sustainability. Zinsstag et al. (2011) express that sustainable development is dependent on the “mutualism of health and well-being of humans, animals and the ecosystems in which they coexist.”

“One medicine” is striving toward becoming conceptualized as “one health.” As “one health,” the development of an advanced framework is more greatly shared and employed through practical implementations with considering the health of ecosystems and their part in global public human and animal health (Zinsstag et al., 2011). On one hand, ecological health, good and bad, impacts the states of well-being and health across humanity and all other animals’ species. However, on the other hand, the components and outcomes of ecosystems are also determined by the health of animals and humans alike.

***Cultural norms and social institutions.*** The current research on social-science and “precarity” can be understood through the genealogy of the “liberal form” of precarity as inequality (Lorey, 2015). This concept has become widely etched in the welfare-state safeguarding of existential precariousness. Lorey (2015), illustrates Castel’s (1997) biopolitical immunizing dynamic in a contemporary manner. This relays how social institutions’ power and influence directly affect the health security of low socioeconomic constituents. When observing public health and health equity, a political-immunological perspective allows for a clear view to examine the threats and danger that are attributed to constructed patterns of social-theory augmentation (Lorey, 2015). The sociological analyses of “precarity” no longer protects the true threats and dangers that loom over societies. The welfare of the state and social benefits become second to that of the individuals and groups in office. Insecurity and precarity have become a “virus.” Modern political and economic conditions in developed countries are angering and harming more societies across sectors including employment, academics, residence, and health – it has become increasingly unacceptable. Lorey (2015) implies that protests against politicians and governments are elicited by precarization, and if nothing is done to ensure health and educational equity, consequences could look like epidemics and pandemics.

Health disparities have various, serious, and multidimensional implications and causes. For instance, they are also a result of financial, economic, educational disparities. Furthermore, these inequities and disparities are tied to the structural training and delivery of medical information and treatment (McMullin & Rushing, 2011). Health disparities and inequalities are largely rooted in health practitioners' predisposed cultural assumptions, racial biases and stereotypes that impact quality of care and success of health outcomes. These attitudes and perceptions have been portrayed and explained in past research pertaining to social determinants of health. McMullin and Rushing (2011) further address and stress the need for greater and more advanced assessment to oversee the systematic and evitable causalities of health disparities and inequities amongst low-income and low socioeconomic populations who are disadvantaged. Their argument also depicts how community and government stakeholders can create effective interventions to reduce such disparities. The utilization of Kilbourne et al.'s (2006) framework for identifying multidimensional social determinants of health projections that result to adversities, disparities and inequities (McMullin & Rushing, 2011). Advocating and combatting health disparities and poor health outcomes throughout various geographic locations and communities, lead these movements and advancements to call out social injustices that create threats to at-risk populations across the globe. By extending public education and resources to promote health, it can help alleviate the high rates of the social and public health injustices found in the medical sector.

Community health education, public health advocacy, and access to healthcare resources are fundamental for low-income and socioeconomic status individuals and families. Wallerstein et al. (2019) convey the efficiency of a culture-centered approach toward community-based participatory research. Their study proposes the first integration and measurement of a culture-

centered approach within research dedicated to academic and community research partnerships. The findings of the study are groundbreaking and can be applied to countless community health research projects that assess the complexities of culture, knowledge, and health (Wallerstein et al., 2019). Thus, implementing and integrating cultural considerations in further research efforts and community health programs and projects may foster and promote health equity for low-income and low socioeconomic individuals and communities.

***Micro and macro politics.*** Wallerstein et al. (2019) present that community-based participatory research can contribute to the value of “power-sharing” and participatory involvement of community members to obtain health, community capacity, policy work, and social justice outcomes. The National Institutes of Health-funded Research has conducted several studies to observe how low-income and ethnic minorities are impacted by policies and legislation and to organize the pathologies of the inequities (Wallerstein et al., 2019). Diverse case studies have represented several multiethnic and racial and other marginalized groups, public health concerns, as well as urban and rural areas across diverse regions. Results indicate how the “oppressive and emancipatory” forms of power function within partnerships in regard to how the oppressive conditions noted throughout histories of advocacy within communities. Establishing trust-enhancing relationships and collaborations, communities can partake in the decision-making processes that will empower and strengthen others.

The study found that there are several components that facilitate the sharing of power and elicit change across the health disparity issue. The components and strategies found are: (1) exposing oppressive external contexts; (2) building from community strengths; (3) paying attention to oppressive academic language and research hierarchies; (4) deliberative communication; (5) structural practices; (6) supporting shared power and community-defined



outcomes; and (7) being the role of primary investigators who conduct these studies (Wallerstein et al., 2019). These strategies can help challenge health inequities and disparities that are external to partnerships and internal within constituent power in order to find and share likeminded values.

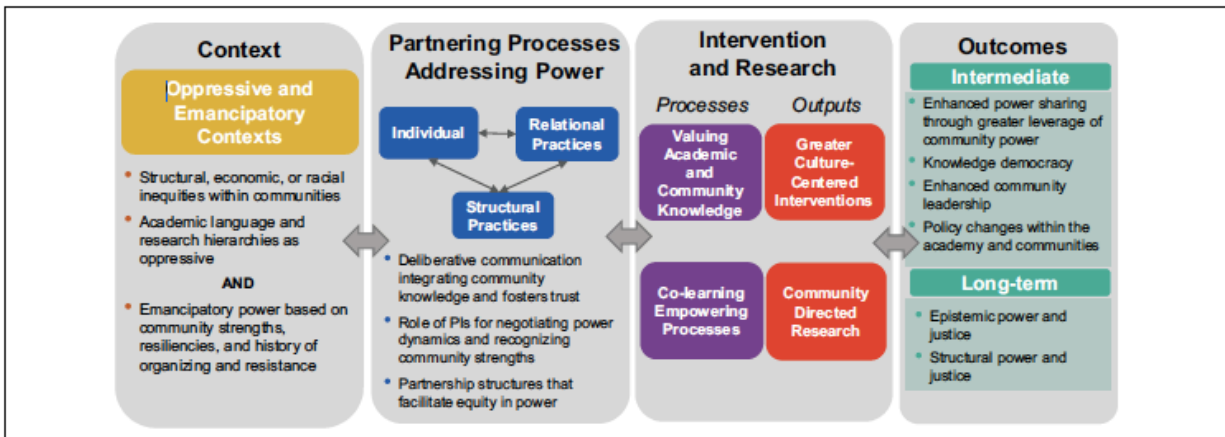


Fig 4: Power in CBPR conceptual model (Adapted from Wallerstein et al. (2008) and Wallerstein et al. (2018).)

**Forces of globalization.** Health disparities and inequities are a global matter of concern. To exemplify, indigenous populations in Canada live with poor and high-risk drinking water conditions that are far below that of the general population. Bradford et al. (2016) examine the health and economic disparities found across Canada’s indigenous and general populations by comparing them. The study’s findings portrayed that there are many existing challenges to the health of indigenous populations and others who live in remote areas. The results shared that “irregular” and low funding, remote and rural locations, and ethical approval processes are some of the obstacles that low-income, ethnic minorities including indigenous populations, that implicate access to clean water, health access and much needed resources. Bradford et al. (2016) further highlight the issues of limited or no access to clean water and healthy ecosystems impact the health of families and groups in a harmful way.

## **Anthropological Research Methods**

Research Methods designed to center health justice and advocacy are at the forefront of academic discourse in the field of public health. It is now commonly understood that health disparities are a public health crisis, and scholars across the nation have dedicated their studies towards understanding what is necessary to achieve health equity. At UC Riverside, the Center for Health Disparities Research (HDR) is a National Institutes of Health (NIH) funded initiative aimed at bringing together environmental scientists, social scientists, and community members to focus on and help reduce health disparities in inland Southern California. The Center is specifically focused on the health challenges and barriers faced by the regions Latinx communities, which comprise nearly half of the area's population. The center's leadership expresses the importance of shifting the focus of research from "on" people to a "with" people, recognizing both the history of research that dehumanized and disenfranchised its "subjects," as well as the sheer complexity of health disparities that require input from a variety of perspectives, (Pittalwala, 2019).

***Research as Resistance.*** While the emergence of research on health disparities is relatively new in Western scholarship, the sentiments of community-engaged research, resistance to dominant structures, and interdisciplinary scope echo voices of scholars who have been swept aside because of their perceived identities. Strega and Brown (2005) discuss the legacy of indigenous scholars, critical race theorists, and feminists (among other marginalized activists), who have questioned structures of power and the resulting health inequity for generations. Strega and Brown (2005) describe the "further inroads into the academy and among researchers," that resistance research has made in the past decade (Strega and Brown, 2005). While progress has indeed been made, the overarching system that incessantly works to reverse it is as powerful as

ever. In community-based participatory research, and any research on community health, it is crucial to recognize that our current efforts of establishing health equity place us on the shoulders of giants.

## ETHNOGRAPHY

### **A Deeper Look Into the US Healthcare System**

Through my search into previous studies, I have come across a distinct schism within our society in regard to the general experience of societal structures such as systems of education, law enforcement, and healthcare. In isolating the issue of structurally fueled health disparities, the question arises on whether this stratification in healthcare may likely be a systematic issue perpetuated by a lack of cultural knowledge and empathy by healthcare providers and the institutions training and employing them. This concern is raised in the 2003 study on “Confronting ‘culture’ in Medicine’s ‘Culture of no Culture’” where Janelle S. Taylor presents findings on the institutional culture of medicine and medical education which prides itself on looking past culture to treat individual patients, a practice which—likely well-intentioned—fails to grasp the significance culture holds so many lives. Healthcare institutions often trivialize the value of culture, and physicians systematically possess merely static and essentialist understandings of their patients’ experiences and perspectives, devaluing “cultural” knowledge while prioritizing medical knowledge as somehow more valid (Taylor, J. S. 2003).

This concept is further demonstrated in Murguía, Peterson, and Zea’s 2003 study on Use and Implications of Ethnomedical Healthcare approaches among Central American Immigrants. In this study, further limitations of healthcare providers in terms of understanding culture and its effects on health are revealed. More specifically, healthcare providers who are not familiar with a worldview or culture outside of their own may encounter difficulty in understanding, treating,

and communicating with Latinx communities in this particular study, but on a larger scale, historically marginalized communities in general (Murguía et al, 2003). Additionally, healthcare providers may not consider ethnomedical approaches relevant in treating health problems. Murguía and Zea conducted a study in 2000 on “The Development of the Cultural Health Attributions Questionnaire” which includes an example of a “Latino worldview” on beliefs which may affect health care utilization, such as etiology, symptom expression, and treatment of illnesses. It also illuminates demographic barriers faced by Latinx populations specifically in this study. These barriers, well-known among communities who have been deemed “other” by standard Eurocentric-American ideals—include limited health insurance coverage, lack of a primary physician, financial constraints, long waiting periods in clinics, inflexible intake procedures, inaccessibility to clinics, inadequate transportation services, limited English proficiency, and the absence of child-care centers. All of these factors as well as a lack of awareness on the part of health care providers widen the divide in health and healthcare in this country. These findings are particularly relevant in the context of health disparities in the Inland Empire of Southern California, because the region is home to Latinx communities that make up 49% of the population.

*“Inland Southern California, currently home to about 4.3 million people, has an acute shortage of primary care physicians, with 35 physicians per 100,000 people. Comprised of Riverside and San Bernardino counties, the region performs poorly compared to other regions in the state in almost all measurable health outcomes — especially in diabetes and coronary heart disease. Among California’s 58 counties, San Bernardino County ranks second worst in diabetes-related deaths; Riverside County is 10th worst in deaths due to coronary heart disease. In San Bernardino County, Latinos*

*have a diabetes-related death rate that is 50% higher than whites. In Riverside County, Latinas have the highest incidence of cervical cancer.”*

-Iqbal Pittalwala (2019)

These alarming statistics indicate a need for attention and intervention designed to relieve the disproportionate burden of health disparities on Inland Empire communities.

### **Lived Experiences of Health Disparities: Putting the Questions into Practice**

Over the past two years, I have conducted interviews about lived experiences within the healthcare system with students from UCR, and worked with a team at the Center for Health Disparities Research at UCR’s School of Medicine to expose slow violence in action at the Salton Sea in Inland Southern California. I have also engaged in continued discussion about the state of the healthcare system and anecdotal evidence of health inequity with Regine Theodore, A Haitian American woman with Autism and a fierce advocate for health justice.

### **Project 1: The Inland Empire**

#### **Community Interviews**

I decided to interview UC Riverside students for this project because of the population demographics of the university and the unique impact of the Covid-19 Pandemic on the student body. A majority of UCR’s students live locally, come from ethnically diverse backgrounds, and receive financial aid from the school. This means that the university’s students are doubly impacted by the fallout from the pandemic—as emerging adults in an unjust system, and as students subject to perpetual conditions of uncertainty at home, at school, and at work during a period of life meant for engagement, self-discovery, and scholarship. I conducted 13 interviews with 10 undergraduate students and 3 graduate students studying at UCR. Of these students, 11 come from ethnically underrepresented backgrounds, and at least 6 identify as queer,

transgender, or gender nonconforming. My hope was that by speaking with other UCR students who have experienced the pandemic, I could collaborate with peers to uncover commonalities between stories of health challenges and barriers to adequate health resources. I began by asking participants about their current health and health history, to get an idea of baseline health among these students. I then asked what considerations must be taken when deciding to go to the doctor, when choosing a doctor, and when determining what course of action to take when experiencing health ailments. The next portion of the interviews surrounded access to healthcare, including if healthcare has been available when needed, whether the school's or private insurance is being used, and what factors each participant considered to be influential in their access to care and health resources. I concluded by asking about general feelings on quality of healthcare received, the US healthcare system as a whole, and thoughts on universal healthcare. I then gave participants the opportunity to share anything else they thought might be important for this conversation on health disparities to include. While the experiences of these students are not intended to be generalized to all individuals from minority backgrounds, patterns that emerged in our conversations reflected those of disproportionate access to healthcare for marginalized communities discussed in the literature review.

## **Findings**

The core themes that my questions intended to cover were:

- 1) General state of health
- 2) Perceptions and views of the healthcare and insurance system
- 3) Access to healthcare and resources
- 4) Personal healthcare treatment experiences
- 5) Thoughts on universal healthcare and ideas for changing the system

The emerging themes from interviewee responses were:

- 1) Healthcare Industry
- 2) Lack of healthcare information
- 3) Universal healthcare

***General State of Health.*** Among the 13 respondents, general state of health varied from very poor to very good, with 3 reporting no acute or chronic health problems, 2 reporting acute health problems, and 8 reporting chronic or chronic and acute health problems.

***Health Literacy/Confidence Navigating the System.*** When asked about their choices and decision-making processes regarding acquiring healthcare, they shared similarities in what they consider when deciding a doctor, how frequently their health is on their mind, and what actions they take if they are feeling unwell. In general, five key factors influenced what the interviewees take into account when deciding on a doctor: gender of the doctor (5 respondents prefer female), proximity of the facility, the provider's communication, listening skills, and demeanor, whether their insurance is accepted, and if the doctor takes time with their patient rather than rushing to the next one. Of the 13 respondents, 9 think about their health daily, 3 think about it frequently, and only 1 does not think about health often. When asked the first thing they do when feeling unwell, none of the participants answered that they would go to the doctor, rather, they would avoid going for as long as possible due to reasons such as fear and mistrust associated with previous medical experiences, feeling like it would be a waste of time and not worth the effort, and unexpected expenses that often arise from a doctor's visit. Instead, participants shared nine different actions they take, many of them appearing several times throughout the responses. These nine health behaviors include (in order of most common response): rest, over-the-counter medication, google/WebMD, "figuring it out," hydrating, listening to their bodies/doing body

scans, drinking tea and taking vitamins, and exercising. Overall, the participants expressed great interest in maintaining and caring for their health, though not necessarily by going through the healthcare system.

***Access to care.*** Out of the 13 interviewees, 6 were satisfied with their access to healthcare, though 3 of those 6 indicated that this had not always been the case. 2 of the 6 who were content with their access mentioned close others who they were worried about because they do not have the same level of access. 3 of the participants shared that their healthcare access was acceptable, but that they frequently faced issues with quality of care, long wait times, insurance technicalities, and limitations surrounding gender-identity. 2 of the respondents do not have access to reliable healthcare and frequently struggle to get the medical attention they need. All the participants shared a general concern over the lack of healthcare access in the country.

***Perceptions, views, and feelings about the system.*** Due to varying levels of access across participants and even throughout some of the participants' lives, valence of emotions regarding the care they had received also varied widely. Some common topics of discussion in this section of the interview were issues with insurance companies, doctors being rushed and treating their patients like a set of symptoms rather than a human being with agency, shifts during the pandemic that added strain to the system and healthcare workers, low expectations about quality of care when going to the doctor, general feelings of anxiety, sadness, and frustration about navigating the system and lack of universal access, and concern over a lack of research for trans people specifically. What was interesting, was that the 3 participants who expressed positive emotions about their experiences also reported feeling lucky and grateful for being able to access care.



*Ideas for change.* When asked about how they would feel about free Community Health Courses being offered, all 13 respondents said they believed this would be helpful and beneficial for many people. Though only 10 of the 13 shared that they would attend courses like these, they all expressed ideas about what kinds of information would be useful to have access to. These ideas included:

- Information about common causes of pain and pain management without the use of opioids
- First Aid skills including CPR, wound care, and blood pressure readings
- Preventive care information like nutrition and hydration, sleep hygiene, mind and body connection, sex education, and drug safety
- Mental health knowledge and resources such as learning to recognize and cope with symptoms of depression and anxiety
- And how to access community resources, navigate insurance and the healthcare system, and advocate for oneself when seeking care

The final two questions of each interview asked the participants about one thing they would change about the US healthcare system if they had the ability to, and what their opinion on Universal Healthcare is. Several responses described the system as a business, expressing that they would change the industry-aspect of the system, and others expressed frustration over the lack of authentic concern from medical providers, sharing that they would hope medical providers would be more compassionate, empathetic, and interested in their voices. Each of the 13 respondents advocated for free universal healthcare. I have included a compilation of narratives gathered from the interviews with thoughts on the system and ideas for change.

**Question: What is one thing you would change about the healthcare system if you had the ability to?**

***Response 1:** I mean, I would make insurance companies go away, and I don't know, allow for like, a more streamlined process? I don't know, because it's not easy. You know, it's not an easy question. But I think definitely getting rid of insurance companies and making it mandatory for doctors to adopt a biopsychosocial approach to health care. So that they focus on the health overall of the person. And also training doctors to like work with the principles of Health at Every Size.*

***Response 2:** Um free access for everyone, I mean, I think it's so weird and gross that we don't give access to health care, I find it so weird that it's not just like a human right. Because everyone should be able to like understand their body and get help for their illnesses and diseases, regardless of if they have money. You know. I guess that's like such a radical idea, but it shouldn't be. And yeah, it's it really It saddens me a lot, um and frustrates me a lot and it's just like one of those things that we just like have to deal with but then people come around trying to change it and I'm so for it.*

***Response 3:** Very simply universal health care and of course I'm not a politician, I don't have the logistics to figure out all the parts of it but it's kind of this idea that it would be cheaper in the long run to prevent people from getting sick. Then the problem in our country, that we have the system of healthcare and honestly we don't care about your health until you get sick and I can charge you to hear you or take care of you or someone can profit off of that. And there's lots of problems, obviously, like healthcare companies have been immensely wealthier in the pandemic situation and that's terrible because this whole idea of trickle-down economics, it doesn't trickle down it goes up. When you compare to other countries that have universal health*

care systems such as in Japan, and all this like yeah being a doctor isn't exactly as like cushy of a job, like doctors in Japan make like, it's not considered a wealthy profession per se. But at the same time, the reason why doctors in the US, want to make a lot of money and feel like their skills are worth it I'm not saying they're not that's not what I'm saying what I just meant is like it goes it's deeply rooted in the whole system. When you go to MED school you go under so much debt you know. People often graduate medical 400 K in debt and you have to work the jobs to make it up for it, and then the interest rates are piling up and it's like. My point is that we have a flawed system from its very core. And it's not this idea of just like paying people more giving everyone how that like yes give everyone a health insurance, but then the questions like who's gonna pay for it that's like. Well it's a lot cheaper to prevent people from getting sick in the first place than it is to treat them. It's like trying to kind of stop a flood, if you have a leaky pipe, patch it while it's still small don't let it like burst and try to shut the water pressure from going out.

**Response 4:** The cost, yes, too many people are going into crippling debt for just simply wanting to live and be treated for their health problems and I think that your income should not dictate whether you live or die or whether you go from living in a home or a safe place to on the street, because of an unexpected random obstacle that you faced medically that you did not expect. I don't think that should cause you to lose all of your savings or, I just don't think that it should cost as much as it does, because I know from other countries that it doesn't have to be this way, and that because of the strain of this people would rather let their problems fester into worse and worse conditions and that's not something that should kill people. I think that going to the doctor is a right that everyone should have, ideally, and that it's completely feasible because we have like the infrastructure for it, we have the resources. And that receiving medicine

*shouldn't be as big of a burden as it is, because, one consequence of having a system like this is that people who are more poor or financially disadvantaged in this society will not undergo the treatment that they need, and as a result, they will be stuck in positions that they are in because they don't have the same resources or benefits as people who are able to afford healthcare do.*

**Response 5:** *It is to be able to give free care to everyone there's so many other countries that do it and the United States has the resources to do it, but we have politicians that don't believe in it.*

**Response 6:** *I would change the profit driven aspect of it and if more doctors were like that Rheumatologist you could sit there with me for an hour and actually like listen to what I was saying, and weren't concerned about needing to see a patient every 15 minutes, maybe more people would get answers like maybe more people would feel heard and, like, I feel, like so many people just get so discouraged that they just don't go back and then they suffer forever, without any answers or any reason, just because, like one doctor didn't listen to them and it is so discouraging or made them feel like they were faking it or made them feel like you know, being a woman or being a person of color or you know being like a queer person like I mean I've been to the doctors with friends of mine who are trans and doctors not being properly versed in how to navigate that situation or just needing to go through so quick that like they they're not actually giving the patients the care that they need, so if there wasn't this profit aspect of needing to see a patient every 15 minutes and if more doctors had the ability to have like a private practice where they could have like that environment where they set the tone and the pace that would be ideal.*

**Response 7:** *Like universally free like free access, everyone should have access to universal health care there's like no reason why anyone should be denied health care. Or like why people here have to pay like hundreds and thousands of dollars for like say insulin and if they don't get*

*it, they die and there's cases like that every day. So, like make it free like health shouldn't be monetary or business-based, its life. Everyone has the right to live just for existing.*

**Response 8:** *Well, like I said, maybe like have more cheaper healthcare or I don't know, maybe free access to healthcare is kind of pushing it, but people need it. I don't know, people have literally had no money for that, they can't spare that, and it's not fair that their health is gonna be like at risk or that they don't get to enjoy their lives as a healthy human being*

**Response 9:** *I would want universal free healthcare for everybody personally. I don't think it's fair that if you don't have insurance you just are in debt for the rest of your life. You have to file for bankruptcy. I have another story actually. so my boyfriend's sister, she has a condition where she like faints a lot and the first time it happened, they freaked out and they took her to the hospital and that family doesn't have the most money, especially since they have a bunch of kids he has six siblings I think, so yeah so the medical bills were way too expensive and his dad had to file for bankruptcy. Just because of one hospital visit. So, like I just think that's not fair, like you should be able to go seek like, 'Why is my daughter fainting' without worrying about 'oh like how am I going to feed my family,' you know, like I don't think that's fair at all. There should definitely be universal free healthcare.*

**Response 10:** *Healthcare is expensive and um the American Enterprise system like capitalism has made it a lot harder for the way things are just because like different drugs are stupendously expensive. Other countries can make it so cheap to just to get—like in Germany, like these prescription drugs cost like fifteen dollars and in the US, it's like one hundred and fifty plus. I think for some it was cheaper to like fly to Cuba to get their medicine then it was to stay in the US and buy it. The flight and paying for everything else was cheaper than that. Which is kind of depressing. But, I think, like funding of where things go should be better. Like I really don't*

*like how we fund fifty five percent of our tax dollars into the military and the next thing is the fact of like how prescriptions and drugs can be capitalized too. So, it's like oh, if they're in control of the market they should have competition so it will be cheaper, but they don't, so, why is everything so expensive now? Like an ambulance is fifteen hundred dollars, might as well call an uber.*

**Response 11:** *I feel like free healthcare is like a really contested topic, I know, like a lot of people like want to keep their private insurance, and I see, to a certain extent, like the reason why people want their insurance to keep their doctors. Like I have Kaiser and I like keeping my doctors that I see at Kaiser, but I also see the greed of the pharmaceutical industry and those private insurance companies. So I think like what I think the solution is to have everybody receive universal health care as soon as you're born and you can opt out for private insurance, but there also needs to be limits on private insurance and what it can cost so it's not just like over-charging those people, even if they want it, you can't cause it's just morally wrong.*

**Response 12:** *I think it just feels like they're running a business that's what it feels like I mean I had an emergency surgery and literally I was like in a life and death situation. I had some woman from Kaiser like telling me to sign a consent form, and this is me like not even like I wasn't really even there you know, and she was telling me to sign it and you know, there was like a brief argument with her and my doctor, because my doctor knows me, you know she knew I had needed the emergency surgery and everything that was going on with me, she just kind of came in saying like you need to sign these papers like online and so my doctor stepped in and was like hey like he doesn't need to sign that like I'm getting prepped like we're ready to go for the surgery. And she was like well if it's not an emergency if you won't prove you know it's a life or death situation like he needs to sign it, we need to get the signature. And then she was like well I*

*already got it though like what are you doing here like you know. And then basically my doctor left, and she was still like I need you to sign the form. And I was like well I can't really sign right now, like she's like it's okay just put a line just put something so I signed, or whatever you know, I was in the middle of trying to make a call to my dad, he didn't always going on, and so I just, I don't know, I didn't like that. I could've signed after, I literally don't even know what the forms said I didn't read it, I didn't know what it was for, I just know I had sign it. I don't know if I was signing off on the emergency surgery, probably, I never got a copy of it like I don't know so, yeah who knows. So yeah, I think it feels like a business, and if it weren't for like the insurance I have, oh another thing is like I used to get injections for hormones. And I didn't like doing those because I had to return every two weeks, and it has to be like that specific day and I had like a really hectic schedule, I was like working full time when I was going to school full time. And so I tried switching to like there's like this other kind of like a cream or something, like gel that you rub on instead and I looked into that, but turns out like I would have to pay out of pocket for that, so I don't know it feels like one-hundred and twenty, like honestly I don't even know the price, I just know that at that time I couldn't afford it and it was just like okay well I'm just going to do injections, and whatever my insurance pays basically.*

**Question: What is your opinion on free universal health care?**

***Response 1:** I think it sounds great. I think it's challenging to pull off. But I mean, I also think that if any country has the means to do it, it's probably the US right? So, it's really just a lack of want.*

***Response 2:** Revolution. Right yeah I mean we've just gotten so far into this like terrible way that we function as a society of like I said a view of having power over everything and, Unless we, until we overthrow that I like I don't know how much, I mean they're just going to keep trying*

*to appease us with more things and I don't know, I'm not super educated on this kind of stuff but, I guess like more of a real answer to that would be working with like lower income and marginalized communities to I guess help them or educate them, I don't even know what you can do, though, it's like they don't have insurance or like they don't have like actual access to health care, like what can you do.*

**Response 3:** *Yeah I think generally universal like healthcare in general, would be really important because, again we can prevent people from having heart attacks early on, make sure that they get preventative measures make sure that they are engaging healthy like managing the blood pressure, before it becomes a heart attack. That is gonna be a lot more effective in the long run, yeah, it's a lot harder to stop the flood there, like the hemorrhaging we already have. But in the broader scheme of things like that's the way to go, I think, also with regard to Community health outreach I think that's a huge one and I don't think it's any one individual's job. It's impossible for any one person trying to fix the system we have. But I do think, with regard to the Community level, there are things that we can do to help better equip individuals to navigate the systems that are in place. And again, this is just making light of a bad situation, but like again to your point about like Community health workers getting them to say like 'Oh, these are the services that are available to you, hey, did you know that you qualify for these things,' but not just giving them the phone numbers and letting them do it, but also like trying to guide them, but again, the thing that comes up is like who's gonna pay for the people to go and support the people who need help, and again, it's because everything is kind of capitalistic and driven by like personal profit and incentives. It's really hard to make money appear out of thin air, and until people want to offer that and put it up for the betterment of humanity, like not just like saying they're for that, like I don't really know. This is why I get really depressed sometimes.*



**Response 4:** *I think that we should implement it, it's not like we can't afford it. We just need to stop treating healthcare as a business and start treating it as like a right that every person should have.*

**Response 5:** *Um, well, I agree, I think that it's something that any First World countries should do. Because there's countries that are considered third world, and they have free medical access.*

**Response 6:** *I love the idea of it, I feel like being someone who has struggled so much with it and being someone who I have to make big life decisions based on my health care, like a lot of people my age don't have to do that, because you know, like my partner is super healthy, doesn't have insurance does not care to have insurance, like she's like 'I'll take the hit on the tax, it's fine I'd rather pay then, than have to pay every month when I never have to see a doctor' and that's all great and fun and I'm really happy that you don't have to pay for health insurance every month, but like I don't have that choice like I don't have that option and the fact that someone, and I've talked to my girlfriend about this, the fact that you can opt out of healthcare makes my healthcare so much more expensive and the fact that we don't have, you know that was like part of the affordable care Act was requiring people to have health insurance, so that the burden would be spread across and so people who really struggle and need it like have the ability to get it at a cheaper cost, but for every healthy person that doesn't put anything into health insurance, all of those of us who have no choice but to have health insurance have to pay so much more for it. So, the fact that we don't have a society where like people understand that concept of, 'okay if we're all putting in a little bit, and even though I might not need to go to the doctor this week, someone else does, and that person, their doctor's visit is going to be so much cheaper, because we all put in just a little bit this month, and we all opted to help each other out*

*by being a part of the system.' But there's so many people who don't need to be a part of the system. They don't you know, aside from weird freak accidents, like they don't have bad health they don't need to see a doctor and they can opt out of that whereas universal healthcare would take that out of the picture. And so it's definitely something that like I feel very strongly about and I'm very jealous of every country that has it and has it successfully, and you know we still fight tooth and nail saying it's not possible when it's like, oh there's so many examples of it working that why is it not possible? Like we're just very selfish people and we don't want our tax dollars to go up. When it's like, okay, but some of us really need this. So um yeah, I want it, I want it really bad, it would make my life and other people's lives so much easier.*

**Response 7:** *Well first off, we know we've gotta shy away from all these privatizations of certain companies being able to have like the rights to sort of patents and plans and not be able to share it with others. Privatization is like really bad and I'd also say like look towards other countries like Switzerland and Finland and, like other countries that are already like those pioneers that are like 'healthcare for all' and are doing like parental leave for their children. I would argue that that is part of healthcare too, like parents being able to stay home with their children after they have a kid but also like childcare itself. Like other places, are even doing free childcare, which the US also doesn't do. So, looking towards other countries that are already pioneering and seeing what has been working for them and what hasn't been working for them. All systems are intertwined and, at the end of the day, this country was founded, based on segregation, discrimination, fear, and patriarchy and just the white supremacy, and so everything that this tokenism involved like it's all coming down to the same thing. It's corrupted and it's a failed system from the start. From the very start it was there, it wasn't going to work, and so now we're here at this point where everything is about money, a business, so the*

healthcare just reflects that, the education system just reflects that, the religion system we have here reflects that, so it's all coming down to the same core concepts that it's just not working. It all needs to be rebuilt from the foundation up.

**Response 8:** *That would be amazing, that would be great, I think everybody would benefit from that I don't see why anybody would object to that, you know, like if its free, like yeah, I think it would be great for everybody.*

**Response 9:** *I just think insurance companies are a scam. I think they're such a scam. Like they're so horrible, and even hospitals, they charge you so much like I don't know some kind of like itemized bills and stuff like that. It's ridiculous, like I don't understand that at all. I just think, I don't know; I don't really have a plan for it, but I've definitely thought about it.*

**Response 10:** *I would love to see free universal healthcare, um individually or yeah. I'd personally do it as like a progressive from the Bay, I'd like to see it. How the economics of it would be working, um, I'm not particularly sure, but I think it should work out. I would like to see everyone get free healthcare*

**Response 11:** *I would just say like, imagine if you were in someone's shoes who didn't have healthcare like if they couldn't afford it or if they weren't eligible for Medicare or Medicaid, because of their immigration status or whatever. Like put yourself in their shoes and realize if you needed the help for a health problem, where would you go? You know, you need access to doctors and people who can practice medicine, so I think the solution to that problem at this point is put yourself in someone else's shoes who doesn't have that access and see what, or if it's someone you love in that situation, imagine what you would want for them.*

**Response 12:** *Free universal healthcare. I always advocate for it, you know, I've had conversations about this. And it's just a human right, and I think you know everyone, like there*

*shouldn't be a difference in the way doctors or staff treat you or how quickly they respond to your needs based off of the kind of insurance, you have, or if you don't have any. And I think I've heard situations where it's like if you don't have insurance like you get billed a lot more and it just doesn't make sense to me because, if anything like those people that can't afford insurance won't be able to afford the higher prices you're making them pay after like a surgery or something. You know it's difficult. People always like bring up 'oh its taxes who's going to pay for it' and this and that. And it's like to me, for me, at least I just feel like when you're part of a society it just comes with it. You know it's like you need the roads, there's certain things we all need that yeah unfortunately they're taking money, and you don't like it. At the end of the day, though it's like we're all living similar struggles. And if you're at a point where you can help others out, I don't know, you might not see it like that. And you know people feel good when they're going to church, or you know gifting money or giving money to people or homeless people or whatever, but they don't feel good about paying taxes, like maybe you should feel good maybe should remind yourself that you're helping the less fortunate, you know.*

From these interviews, I gathered three common themes that arose across the responses: treating healthcare as a business causes major problems in the system, the difficulty of accessing medical knowledge and navigating the healthcare system, and that universal healthcare is a basic need that should be a right. The students of UC Riverside are very much aware of health inequity on a personal and societal level. Each participant interviewed offered a unique perspective on why the healthcare system is insufficient, though they were on the same page about the fact that it is. It is clear from these conversations that general sentiment surrounding access to healthcare among these individuals is that the system is in dire need of change.

## Project 2: The Salton Sea

“Certain lives are grievable, and others are not, and this works to sanctify the violence we inflict, and to disavow any conception of our own precarity,” asserts Judith Butler in an interview with Nelly Kambouri on the diminished value our society places on the lives of individuals characterized as “other,” (Butler & Kambouri, 2018). The United States has a notorious history of responding to tragedy, hardship, and disaster with a polarization of communities based upon outdated categorizations placed upon its people with the intent of maintaining the societal hierarchy entrenched into every aspect of life. Butler (2018) exemplifies this unfortunate reality with an assessment of the US government’s response to national crises such as 9/11, where instead of uniting its population under the commonality of vulnerability and uncertainty, it capitalized on fear and disavowed that very vulnerability while regulating our understanding and response to tragedy. Underlying nationalism prevails as some deaths are sanctified, and others, which occur every day as a result of systemic injustice, remain ignored. This is slow violence in action, as those at the top of society dictate which lives are to be memorialized, and which are simply unfortunate casualties of neoliberalism.

Butler’s (2018) concept of “grievable” versus “ungrievable” lives is evident in the ecological disaster of the Salton Sea in the Eastern Coachella valley of Southern California, one of the many communities which serve as examples of systemic neglect and intentional dehumanization of populations deemed unworthy of basic human rights. Necropolitics entails a system in which some are made to live, and others are made to die to ensure the prosperity of the living. The communities of the Salton Sea are denied access to a habitable environment while wealthy surrounding cities such as San Diego and Palm Springs flourish off the very resources allocated away from these communities. As Butler (2018) puts it, “any decision to enact violence

or to refuse violence has an ethical dimension, since it pertains to conduct and to the kind of rationale we give for whatever relation to violence we take,” and the blatant disregard for the environment of the Salton Sea speaks volumes for this nation’s stance on the matter.

My work at the Salton Sea explores the health consequences of colonization and ecological degradation on the individuals and communities living in the region. As an undergraduate researcher with the Center for Health Disparities Researcher at UCR, my team and I have investigated the history of health policy, environmental justice, and resource acquisition surrounding the Sea. Through a series of Story Maps, we seek to expose the mechanisms of slow violence that have brought on the decline in health of the sea and its inhabitants along with it. The valleys surrounding the sea continue to be impacted by generations of systemic racism, industrial agriculture practices, and settler colonialism, facing inequitable access to resources needed to recover from these ongoing processes. In these Story Maps, we address the efforts of local community-members who are fighting health disparities and environmental injustice on the ground, interview researchers studying the asthma-like symptoms that occur due to environmental pollution at the sea, and discuss policy and plans in place to restore the health of the sea and surrounding communities. My team and I hope to use our Story Maps as a base for further discussion on the health crisis at the Salton Sea, and will be presenting our work at this year’s UC Global Health Conference to invite attention to the need for action.

The Salton Sea is another example of compounded health disparity. The communities in the region are mainly of Indigenous and Latinx background and are frequently overlooked in the creation of policy for the area. The California and US governments have repeatedly sacrificed the health of the sea for profit, resulting in environmental hazards that now threaten the health of these communities. The difference between this region and neighboring cities of Palm Springs

and San Diego is that the people living at the sea have been racialized as inferior, while the demographics of the latter two better fit acceptable standards of whiteness. This juxtaposition is powerful, as it outlines the direct impact of systemic injustice on the health of individuals and the environment.

In “Radical Hope and Rain: Climate Change and the Mental Health of Indigenous Residents of Northern Australia,” Hunter (2009) echoes sentiments of necropolitical action—or inaction—and reflects the persistent marginalization, or “cultural exclusion” which actively restricts access to means of achieving for particular population subsets (Hunter, 2009). His work extends globally and in one account, describes how the efforts of indigenous Australians—which span millennia and can be said for many other forces of ecological preservation by native populations—have always contended with European colonizing forces; climate change simply being the newest of these crises. This cyclical ecosystemic injustice takes a toll everyone, exponentially more so for those already experiencing precarity.

### **StoryMaps**

[Exposing the Desert Series - Overview \(arcgis.com\)](#)

## **Project 3: Overlapping Inequities**

### **QTPOC Health**

Throughout the history of the United States, queer people have been outcast, vilified, pathologized, and denied conditions necessary for a safe and healthy life. Though social and political progress has been made by generations of queer individuals, communities, and activists fighting for the right to live, disproportionate health disparities among these communities is still widespread. Health outcomes within LGBTQ+ populations are stratified by class, race, and intersecting identities. These health disparities are influenced by many factors, including stress

and health problems associated with coming out, lack of mental health support and resources, homelessness, and drug addiction and are exacerbated for lower income queer individuals (Hagai et al., 2020). Oftentimes in LGBTQ organizations and related scholarship, sexual identity is used as the primary aspect of identification for these individuals, reducing their humanity down to one aspect of who they are. Furthermore, even with improvements that have been made in public opinion and legal recognition, homophobia persists. McNair (2017) argues that, “multiple cultural identities influence queer health and wellbeing in both positive and negative ways (McNair, 2017). They do so through their influence on self-perceptions, on social inclusion and on citizenship; that is, on how we interact with, and contribute to, the world.” Despite this, queer issues are often overlooked in studies on health disparities, and not taken into account within the framework of Social Determinants of Health. McNair (2017) explains that integrating issues of queer health into the dominant framework for studying health inequity would help, “overcome the problematic silence on both queer and multicultural, multi-faith health in health care, research and policy arenas.” Given that racialized and gendered identities subject to discrimination, marginalization, and vilification are difficult to conceal, they frequently act as additional impacts on a person’s agency that may already be restricted by intersecting marginalized identities.

In the study of health disparities, it is important to recognize the ground-breaking force of the queer-trans people of color (QTPOC) community. As Hsu (2021) puts it, there is no revolution without the collective power of the lessons from Third World Feminisms, such as the Third World Women’s Alliance (TWWA) in the 1960s-80s, and present QTPOC communities.

*“It should go without saying that any movement toward the “liberation of women of color” must also include and listen to trans women and femmes. This, too, is an inheritance from queer of color elders. The Combahee River*



*Collective taught us to center Black women’s freedom “since our freedom would necessitate the destruction of all systems of oppression.” A world where Black and Indigenous trans women and femmes are free would be a world without anti-Blackness, cissexism, and misogyny—and the institutions that enforce them, including police and prisons, discriminatory housing and healthcare policies, and educational conventions that erase the contributions of Black trans women to gender and racial justice. The experiences of trans women of color, cis queer women of color, trans men of color, and trans men and nonbinary people of color—for all their differences—converge at the boundaries of womanhood, this dividing line that colonial regimes designated to mark us as Other. This boundary is defined by the strictures of white femininity, which have always rendered women of color as excessive and queers as aberrant. This is the line we have always already crossed. The ways we experience the border and the consequences of its violations are not equal. We are, however, all invested in its eradication.”*

*-V. Jo Hsu (2021)*

In the eyes of white, westernized American culture, “us” and “them” are used to distinguish “white respectability” from “brutish masculinity that justifies any violence, or a bridled femininity subjected to white whims and desires,” which queer and trans people of color are portrayed as in dominant narrative. This dichotomy of perceived existence, this petrification of what it means to exist as an “other,” is not only prejudiced but dangerous. This dominant narrative does not exist without consequences, to which we can attribute many of the barriers to health that queer and trans people of color encounter. Some of these consequences include institutions that pathologize queerness, tracing back to queer conversion camps aimed at “suppressing the queerness” out of people. Psychosocial consequences of these camps last in the collective memory of queerness and haunt the healthcare system to this day. National surveys indicated that exposure to this form of torture unsurprisingly resulted in “loneliness, regular

illicit drug use, suicidal ideation, and attempted suicide,” (Goodyear et al., 2021). Despite these incriminating outcomes, the remnants of this practice remain critically unaddressed in public health research and policy. Furthermore, the US healthcare and health research systems hyper focus on sexuality as the key component of LGBTQ+ health. 56 percent of LGBT health articles in 2004 concerned HIV and sexually transmitted diseases in gay and bisexual men, and research is often directed towards health conditions that pertain to sexual health or functioning, colon and rectal disease and prostate cancer among gay men, and cervical and breast cancer among lesbian women (Peel and Thomson, 2009). Now is this actually because these populations disproportionately experience these health issues? Or this just another manifestation of biomedical discourse which has constructed an image of homosexuality as a deviation from proprietary norms, marking it as a red health flag? The healthcare system’s role in upholding and reinforcing harmful stereotypes in the public eye is one of great volume. Rather than devote attention to the lack of knowledge, resources, and mental and physical care, the current system continues to destabilize the lives of queer and trans people, especially those of color. The queer community has played a central role in setting precedent for health advocacy and taking initiative to get their health needs met. However, this incessant battle is not sustainable. Barriers to health influence all aspects of life, and QTPOC lives are at constant risk. Oppression, prejudice, discrimination and violence result in acute and chronic stress of victimization, lack of health resources, and ultimately poorer health outcomes (Lund & Burgess, 2021). As we move forward in working to achieve health equity, we must not forget to include the lives, voices, and rights of queer and trans people of color.

***Community Voices*** A number of my interviews conducted with UCR students included accounts of experiences as a queer or trans person in the healthcare system. These individuals

reveal specific barriers within the system such as broad assumptions and overgeneralizations of queer identity and health needs, a lack of mental health support that feels genuine, safe, and accessible, and limited research on the various nuances in health of queer and trans people as opposed to cisgender heteronormative people. I have included excerpts from our conversations to offer space for their stories.

*“I facilitate an emotional support group for the LGBT community and I prior to like being a facilitator in that group, I didn't even know that that was available. Being like a queer kid, like I would have benefited from this group, had I known, it was a thing. I think what comes also with having these like Community driven aspects of healthcare is also finding a way to make sure that people who need to know about them do. And I think that's a struggle, because I feel like there are a lot of resources and things that people just don't know are out there and also a lot of it comes through church environments and for a lot of people, if you're not part of a church environment, you don't know that those things are available and especially for like queer kids, they're generally not in the church, and so they're not knowing that those things are available, so I think part of coming up with ways of like Community driven access to healthcare is also making sure that people know they exist which is like such a hard part of it, because things already do exist and people don't know that they're there.”*

*“I think it's difficult because on the one hand, I feel like because you know I have access to private insurance like I get I've been treated fairly well but I just think like for a trans person I feel like it's been a smooth transition with my doctors, just because they're on the same page as me. You know they're like really accepting of my pronouns and*

everything. But I think overall my issue is not with my personal doctors, but just overall is the lack of research with trans people, and you know their health. Because when I started testosterone hormone therapy, prior to starting I wanted to know the effects on you know what it would do to my body like would I not be able to have kids anymore, what would like, how would that be and basically they're just like well, we don't we don't really know like we don't have enough research we couldn't tell you, we just know that we advise for you to like go through IVF and store your eggs prior to starting hormones and I was like, okay, you know, I think that kind of postponed my hormone treatment because I was like debating it and a reason why I didn't go through it there was because at the time it's like private insurance and IVF and that process is separate like you have to pay out of pocket. It's as if you don't have insurance, so you have to go to an actual fertility clinic and it's the same for women, you know it's the same for women and trans men and, obviously, you know, I was kind of young then and didn't have the money for it and really eager to get on hormones, because I wanted to treat my dysphoria. So I opted out of it and then like maybe like a year later I'm seeing on the news like oh some trans guy with testosterone got pregnant was able to get pregnant and they had a kid and then there's like this other trans guy that was able to have kids. So I'm just like, so can I have kids or not? I still don't know. I actually I actually stopped hormone treatment, because I want to have kids and I think that it's just kind of like they're offering help by treating your dysphoria but at the same time, I feel like they can be putting more work into doing research with you know the effects on your health, overall. I think they need to do more research; I think it would be helpful. And you know like I still don't know like I got off of hormones and they're like, 'okay well we'll run

*some tests' and I was going to start again like I got the injections, and everything and they're like kind of like 'okay well we'll see how it goes' like 'if you're having a period like that's a good sign' but kind of like there's no guarantee to it or like who knows, maybe I go in and they end up taking out like less eggs than maybe someone who hadn't gotten on testosterone, or no eggs. I literally have no idea, they have no idea. So, I really don't like the uncertainty around that."*

*"Now that I think about it, when it comes to trans people, I think doctors, and teachers, have like this general idea of what it means to be trans and so sometimes when I would go get my hormones my doctor would be like 'oh hey when do you want to start like further surgeries, like bottom surgeries, like we're ready for you' and this and that, and it was kind of just seen as the next step. And I think, as a trans person, what I came to realize is like, you know we're not all the same, we don't want all the same things. Someone can be trans without going through the medical process of hormones or any surgeries or all the surgeries like, we're just going at our own pace, and I think they go based off of the assumption that like, we just want to do it by the book. Every single thing. And so I kind of felt like, not pressured, but like, that's awkward, I think he assumes I want it. Which I think is something I had on my mind, you know, but not at that point in time. I hadn't even thought about that. I had had one surgery, and yeah I think for healthcare workers, maybe they should know more about how we're not all the same, and we don't want the same things, and that it's okay and we're still trans."*

## **Disability Advocacy**

When met with existing health disparities stemming from systemic injustice, having to manage disability in a system that provides the bare minimum to those most in need can become incredibly strenuous. Barriers to healthcare are not lessened for individuals with disabilities, if anything, they are magnified. People with disabilities are regularly omitted from health research and policy. Albeit comprising one-eighth of the US population, people with disabilities are rarely included in sociological studies of inequality, (Shandra, 2018). This may be partially explained by a lack of distinction made by researchers between health and disability. A person with a disability obviously still experiences health and illness, and as Shandra (2018) highlights, is subject to differences in health access, health status related to a, “history of wide-ranging disadvantages, which are avoidable and not primarily caused by the underlying disability.” Furthermore, assumptions that disability is associated with time spent in non-market work, in other words, that people with disabilities do not contribute to the workforce, are harmful, offensive, and correspond with the hybrid model of disability, which recognizes the roles that health conditions and social factors play in one’s experience with a disability. People with disabilities fall into the western heteronormative category of the “other” and are systematically discriminated against in the healthcare system.

**Community Voices.** One of my interviews documents an experience shared by a participant with a disability and their experiences with accessing healthcare.

*“Obviously when I first needed surgery, I didn't have insurance, so going like two years, not really being able to walk and not having access to anything, like that was really really difficult. And being an overall, like outside of my condition, a very healthy person I'm just like, I don't really need to go to the doctor, very often. But I have to*

*make sure that I have insurance, where I can see a podiatrist where I can see an orthopedic surgeon, where I have access to people who can help me when it becomes necessary, and because I have no idea when that's going to happen. I've had like fairly crappy insurance for a long time because I'm poor. So, I don't know, like now I'm in school, I have the school's and insurance through my scholarship. I have access, right now, but not as much as I need. So, it's like there's still limitations, even though I have good insurance right now. And then also you know, I regularly have to do, physical therapy every couple of months, and even though it's decently priced it's still like every week you're shelling out money to go to physical therapy, which, I can't afford to do being a part time worker full time student. I've got rent to pay, I've got a dog that needs a lot of attention and money. so it goes in and out it's definitely like I am someone who purposely makes sure I have insurance that will make it so I can see the doctors I need to see, but there have been points in my life, where I didn't have insurance and didn't have access to that at all. And then, even now, with my insurance, there's some doctors who still won't see me. I feel like I have a lot more than a lot of other people do, and I am grateful for that and, like I'm grateful for the access that I do have even though I'm regularly very frustrated with it."*

**Disability Rights.** Regine Theodore is a compassionate, intelligent, vibrant, insightful, autistic Haitian American woman. She lives in Pennsylvania and loves horses, skiing, boating, being out in nature, and speaking with her loved ones. These are the things that bring her joy day-to-day, and also, the things that keep her alive. Reggie is put in danger daily by people who are unwilling and unable to recognize the severity of her condition and listen to her when she shares her needs. When under extreme stress, it is not uncommon for her to experience catatonia,

battling periods of paralysis and debilitating overstimulation. When seeking help, Regine has been met with disdain, condescension, and invalidation of her pain, her needs, and her existence. She is frequently in need of medical care but has found herself without proper treatment time and time again. In a recent encounter at York Hospital in Pennsylvania, a medical procedure turned into a healthcare nightmare when hospital staff refused to provide necessary accommodations for Regine's treatment and told her she would not be allowed to stay the night at the hospital even though her situation called for an observation period post-surgery. Since she did not have any family nearby to "escort" her home, she was denied treatment despite her need for care. Unfortunately, this type of experience is not uncommon for Reggie, and she has fought tirelessly to advocate for disability rights while simultaneously combatting the structures in place that threaten her survival. Regine's intersecting identities categorize her as an "other" in the eyes of the American system, an idea which implies that her experience is a product of her actions, not systemic oppression. This dominant narrative could not be farther from the truth but the impact of its implications remain all the same.

The issue of compounded health disparities from intersecting identities is one without nearly enough attention in health research. Given how challenging it is to receive quality care as a disabled person, a queer person, or a person of color, what does it mean when someone who identifies as any combination of the above is in need of medical attention? Reggie's story is but one example of the ways in which the US Healthcare system discriminates against marginalized individuals. Comorbidity of disability and chronic disease is associated not necessarily with a greater predisposition to disease, but with barriers to health resources such as preventive screenings for cardiovascular disease and cancer and higher total medical expenditures when able to access care (Reichard, 2011). My future directions include creating a podcast with Reggie



to engage in further discourse on the barriers present within the healthcare system, especially to those with minds and bodies that work a bit differently than the rest of the population.

## DISCUSSION AND FUTURE DIRECTIONS

How do we understand health disparities both as a holistic concept and as the sum of its parts? How do we pay proper recognition to the efforts of the past that have gotten us to the place of free expression that we are in today, while also addressing the pieces of the puzzle that are still missing, broken, or difficult to recognize? From my research, I have come to see health disparities as a cyclical structure built into the foundation of the United States. As the European colonizers committed genocide on the Indigenous peoples of North America, they confiscated land and forced the enslaved Africans they kidnapped from their homelands to tend their crops, raise their children, and fulfill their obsession for violence and superiority. The 18<sup>th</sup> Century turned into the 19<sup>th</sup>, and newly declared “Americans” reenacted the treacherous habits of their European Ancestors, raping and pillaging across the globe on a mission to become one nation above God. With their voracious appetite for expansion, leaders of the land of the free and the brave used their industrial skills to mass-incarcerate, mass-impooverish, and mass-desecrate the land and people of the world. We are in a time where the actions of colonial capitalists are facing their burden of debt. The planet is dying, and along with it, the life on it. Our atmosphere is slowly suffocating us because of the fuel we burn to enjoy lives of excessive consumption. The oligarchy of United States billionaires has hoarded enough capital to establish a universal healthcare system, pay off student debt, and still maintain billions of US dollars on the other side. This is the reality of wealthiest nation in the world, who hides its human rights violations under a boisterous attitude of libertarian grandeur. The tragedy of the situation is the people that

are impacted by the global health crises brought on by colonial capitalist greed are those forced into systems of imperialism that leach off the life force of their homes and communities. Those perpetuating the destruction of the planet and its inhabitants do not have to face the consequences of their actions. They run the country, the global economy, and the mechanisms that maintain a system of chronic inequity. They watch from afar, from the mansions behind their manicured lawns, judging and ridiculing those forced to survive in the conditions of scarcity they have created.

I have found that the way we heal is very different from the way we talk about health. Though healthcare has been adopted into international treaties of Human Rights since the 1940s, the United States has yet to prioritize this basic need as a legal right. Our health institutions are filled with over-worked laborers who spend more time filling out paperwork and hustling from room to room in under-staffed and under-funded hospitals and clinics than engaging with the ailments of their patients, and patients burdened with the dread of the having to pay the inevitable fortune associated with a visit to the doctor. How is it that the wealthiest nation in the world is unable to provide suitable healthcare for all its people? Maybe the issue is not a matter of ability, but of intention.

In identifying and shifting any one tangent outcome of the inequity cycle, it is necessary to factor in the reality of slow violence in our perceived image of the circumstances. Whether we are looking at health disparities, lack of funding for education, interpersonal and institutional discrimination, or confiscation of indigenous lands and people to fuel the capitalist machine, we must recognize the roots of all of these issues in the foundation of the United States through centuries of gradual genocide. The Sun never sets on the American Empire, and with the exponentially expanding role of technology in globalization and development, the trajectory of

our progression is alarming at best, catastrophic if left unchecked. My hope for this journey moving forward is to better understand the specific moments that provide a window of opportunity to create change within a powerful system such as the United States, and collaborate with others passionate about justice to determine how to go about these changes so as to not adopt the same power dynamics that currently exist.

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## APPENDICES

### 1. Interview Informed Consent Form

Isabelle Swanson  
Honors Capstone Project  
Community Engagement &  
Health Disparities

#### Informed Consent Form

**Project Title:** Community Engagement and The Unification of Commonalities in the Face of Oppression: A One Health Perspective on Collective Healing and Societal Growth

**Purpose:** The purpose of this research project is to document the lived experiences of individuals in the US healthcare system as well as to contribute to the unraveling of the generations of systemic injustice that have allowed inequitable health outcomes to persist. Through community-engaged research, I intend to collaborate with my community to address barriers to health and healthcare and develop a counter-narrative of resilience in a broken healthcare system.

**Procedures:** Participation in this study will include filling out a form with basic demographic information as well as a conversation with me that will last between 15-60 minutes, depending on how long you would like to talk. If possible, we will talk in person, otherwise our conversation will take place through zoom. You will be asked a series of questions about your experiences with your health and within the healthcare system. With your permission, our conversation will be audio and or/video recorded. You may still participate in this study even if you decline either or both types of recording. In these cases, I will be taking notes during the interview. You are free to answer or not answer any of the questions asked during the interview.

**Risks:** Risks for participating in this study include feelings of anxiety or worry that may arise from thinking about your health and the challenges that you may face within the healthcare system.

**Benefits:** You will not directly benefit from your participation in this study; however, your participation will contribute greatly to my capstone project as well as to the growing body of knowledge about health disparities in your region.

**Alternatives:** Your alternative to participating in this research study is to not participate. If you choose to withdraw from this study, please contact me to let me know. If this is the case, data that you previously provided to this study will be destroyed.

**Voluntary participation:** Your participation in this study is voluntary. You can decide to participate or not participate, or to withdraw from the study at any point.

If you have questions about this project, please contact me at (909) 809-0252 or [iswan001@ucr.edu](mailto:iswan001@ucr.edu).

Please sign below if you agree to participate in this project.

**I agree to be interviewed and to have my data used for the purposes described.**

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## 2. Interview Guide

Isabelle Swanson  
Honors Capstone Project  
Community Engagement &  
Health Disparities

1

### Interview Guide

Thank you so much for agreeing to answer some questions about your experiences within the healthcare system. My goal is to be able to gather narratives of a cohort uniquely affected by the impact of a global health crisis coupled with the typical changes that accompany this time in our lives. My questions are intended to understand your unique perspective on your personal health, your access to healthcare, and your feelings and experiences surrounding the kind of care you have access to, as well as your thoughts on the US healthcare system as a whole. As we go through this interview, please feel free to mention anything you feel is relevant and that you are comfortable sharing. The sensitive nature of this topic may bring up feelings of anxiety and worry, and you are free to skip any questions that you do not wish to answer. Thank you again for your help on this project. Do you have any questions before I begin recording?

#### Start Recording

I am here with participant number \_\_\_\_\_ on \_\_\_\_ at \_\_\_\_\_ pm.

Before we start, I'm going to briefly go over the consent form that you signed.

#### Review Consent Form

With that, do you have any questions or concerns before we begin?

Okay great! Do I have your verbal consent to participate in this study?

I'm going to begin by asking you some questions about your personal health. Do your best to answer honestly and feel free to ask for any clarifications.

- 1) How is your health currently?
- 2) How would you describe your health history?
- 3) What are some factors do you consider when deciding on a doctor?
- 4) How frequently do you think about your health?
- 5) If you are not feeling well, what is the first thing you do?
  - a. What is the first thing you tell others to do if they are not feeling well?

Now I'm going to ask you some questions about your access to healthcare. While you're answering, I would like you to consider if there are any parts of your identity that may impact the healthcare you have access to and quality of care you receive.

- 6) To what extent do you feel you have been able to access healthcare when you have needed it throughout your life?
- 7) What factors do you feel have influenced your access to healthcare?
- 8) Since coming to college, how has your health insurance changed?
- 9) If your community offered free health courses, would you attend?
  - a. If yes, what would you like to see?
  - b. If no, what is stopping you?

### Interview Guide

Thank you again for answering my questions. We are almost finished, I just have a couple more questions to ask you about your general feelings about your experiences within the healthcare system and the healthcare system as a whole.

- 10) In general, what are your feelings about the healthcare you have received?
- 11) What is one thing that you would change about our healthcare system if you had the ability to?
- 12) What is your opinion on free, universal healthcare?
- 13) Do you have anything else you would like to share?

Okay, that's everything! Thank you so so much for all of your time and energy in answering these questions. Your words and experiences are an invaluable contribution to this project, and I am truly looking forward to producing the final product. If there are any questions, comments, or concerns that come up, please don't hesitate to reach out.

Stop Recording