PART 1

Context and Background

CHAPTER 1

Introductory Frameworks, Definitions, and Theories for Health Justice

LEARNING OBJECTIVES

By the end of this chapter you will be able to:

- Discuss the frameworks, definitions, goals, values, and ethics of the fields of medicine, public health, and law and how these relate to health justice
- Explain key terminology used by scholars and advocates associated with race, sex and gender, and disability
- Describe some critical theories (race, feminist, queer, and disability) and how they have been applied to medicine, public health, and law and ultimately to health justice

Introduction

This text is designed for a wide range of disciplines and readers, as noted in the Introduction. One of the challenges of confronting and addressing health injustice is that so many factors, systems, and players converge along the way to produce the inequities that harm health. Indeed, if health justice is to be achieved, disciplinary siloes (between and among medicine, public health, law, and public policy) must be dismantled and intersectoral solutions must be collaboratively identified and implemented. This chapter is designed to build some common ground among disciplines and professions to facilitate better understanding of one another's language, goals, values, and practices.

But health justice also requires deep reflection about how power is unevenly distributed among people in American society and how this leaves groups of people marginalized and silenced based on their socioeconomic status, racial or ethnic identity, sexuality, gender, and/or disability. To explore how systems of power

exclude particular groups, this chapter also presents how critical theories—critical race, feminist, queer, and disability theories—interrogate the exclusion and marginalization of people considered to be different from the "norm." Linking these theories to health, this chapter investigates how these theories inform and can be applied to medicine, public health, and law to promote health justice.

We begin the chapter with some foundational definitions to create a common understanding of terms as we use them in the text.

Health, as defined by the World Health Organization, is "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."[1]

Health care inequalities are "differences in the quality of health care provided that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions. These differences would include the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels."[2]

Health inequities are "differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age. Health inequities are unfair and could be reduced by the right mix of government policies."[3]

Social drivers of health are "the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."[4] We intentionally use the word *drivers*, rather than the more common *determinants*, to acknowledge the complex causal pathways between and among social, environmental, and biological factors that influence the health of individuals and populations.

Health justice means that all people have the opportunity to reach their full health potential. It recognizes that individual and population health and well-being are primarily driven by upstream structural factors (i.e., laws, policies, practices, and systems), not by the individual behaviors or choices of those in poor health. Health justice addresses health inequities and health care inequalities by recognizing the human rights, civil rights, value, and dignity of all people. Health justice requires self-determination for those who have experienced exclusion, discrimination, and stigma; demands structural changes (in law, policy, practices, and systems) that promote equitable power-sharing across all groups; and, ultimately, secures equitable, health-promoting conditions and communities in which all people can thrive.

How people define health justice may be influenced by their particular vantage points and experiences. For students, the discipline they are studying and/or profession they are preparing for may affect their perspective and understanding of health justice. To bridge understanding and facilitate inquiry and discussion across disciplines, we offer an overview of the frameworks, definitions, goals, values, and ethics of medicine, public health, and law. We start with how these disciplines traditionally have been defined and framed and then explore how they are changing, including how each is confronting and addressing concepts of health justice.

Medicine, Public Health, and Law: Frameworks for Health Justice

Medicine

Frameworks and Definitions

Typically, people think of medicine as primarily concerned with the diagnosis and treatment of disease. In the United States,

it is often said that medicine is both a science and an art, meaning that clinicians apply scientific knowledge when diagnosing and treating disease, but they also draw on their own experience and intuitions to help guide them. Traditionally, medicine has been primarily associated with doctors and patients. But medical care involves a range of professionals and practitioners, including nurses, social workers, physician assistants, medical assistants, direct care workers, community health workers, and many others. Increasingly, medicine is becoming a team-based multidisciplinary affair, drawing on the knowledge and expertise of various players. Therefore, when we discuss medical professionals in this text, we are referring to the various practitioners who make up the medical team, not just doctors. Furthermore, medicine cannot be understood in a vacuum. Patients and health care providers exist within larger systems—not only the health care system, but also the political system, legal and regulatory systems, and the many other systems (e.g., educational, criminal justice, environmental) that influence health and health care. **Figure 1.1** demonstrates the biopsychosocial model of health, which incorporates the many factors affecting health.

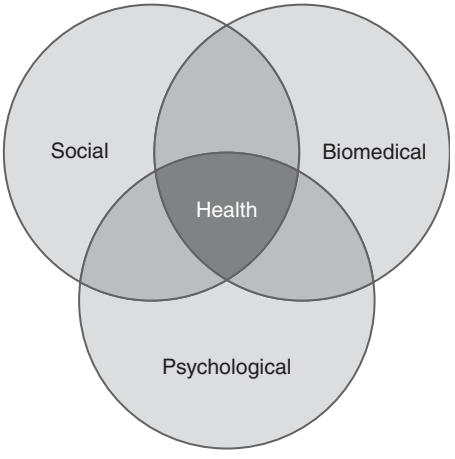

Figure 1.1 The biopsychosocial model of health

Goals and Values

How one defines medicine and constructs its frameworks depends first on articulating its goals. The goals of medicine, no doubt, vary based on social context (i.e., where and when medical care is being delivered) and on specialty (the type of medicine being practiced). Nonetheless, scholars have proposed four basic goals of medicine, so we begin with these:

1. Preventing disease and injury and promoting and maintaining health
2. Relieving pain and suffering caused by maladies
3. Caring for and curing those with a malady and caring for those who cannot be cured
4. Avoiding premature death and pursuing a peaceful death[5]

You may detect in these goals a strong focus on the relationship and interaction between the clinician (physician, nurse, or other health care provider) and the patient. But, increasingly, American medicine is embracing broader social goals for clinicians that extend beyond the care of individual patients. For example, in 2001, just after the attacks of September 11, the American Medical Association drafted the *Declaration of Professional Responsibility: Medicine's Social Contract with Humanity*, in which it articulated a more far-reaching vision of clinicians as advocates for "social, economic, educational and political change" in addition to their obligations to care for individual patients and contribute to medical science. Indeed, the declaration states that "humanity is our patient."[6] Though the declaration speaks specifically about physicians, its principles can be applied to all medical professionals.

Nonetheless, the notion that physicians and other health care professionals are obliged to use their skills and knowledge to improve society was certainly not new in 2001. Rudolf Virchow, a German physician, anthropologist, pathologist, writer, and politician, first coined the term *social medicine* in the 1800s to describe how social factors influence and harm health and inequality as a causal factor in disease. Virchow explained that:

> Medicine is a social science, and politics is nothing else but medicine on a large scale. Medicine, as a social science, as the science of human beings, has the obligation to point out problems and to attempt their theoretical solution. . . . The physicians are the natural attorneys of the poor, and the social problems should largely be solved by them.[7]

Social medicine, therefore, extends the medical provider's role well beyond the exam room or lab into the social sphere, including weighing in on public policy, law, and politics. While not all of the medical community embraces social medicine, it has become increasingly adopted in primary care, which centers on holistic and preventive approaches that acknowledge and work to help address social factors related to health. In recent years, some in primary care have embraced a "population medicine" perspective that is concerned with patterns of disease among a population of patients and employs data (including data related to broader social factors) to better understand those patterns.[8] The ethical obligation of physicians and other health care providers to use their knowledge and skills to address their patients' social needs and to promote public policy reform is still debated, but it has gained traction in recent years. Later chapters in this book discuss how medical providers are working both within clinical settings and outside them to address health inequities and injustice.

Ethics

The term *biomedical ethics* emerged in the 1970s as a way to apply philosophical moral principles to ethical dilemmas in medicine. Tom Beauchamp and James Childress's book *Principles of Biomedical Ethics* describes four ethical principles that they argue should be applied to medical practice and biomedical research.[9] See **Table 1.1**. Beauchamp and Childress intend for all four principles to be applied equally to an ethical dilemma; if one or more of the principles must be violated, the violation should be minimal. The principle of autonomy invokes individual rights: the right of patients and research subjects to make their own decisions, without interference from medical professionals, family members, or others. The principles of beneficence and non-maleficence speak to the obligations of medical professionals to ensure that they are acting in the patient's best interest (not their own) and without harm to the patient. Beneficence and nonmaleficence intersect with the principle of autonomy in that medical professionals should not paternalistically make decisions about a patient's health based on what they believe is best when those decisions violate the patient's rights and values. The principle of justice concerns equal treatment of individuals and populations (without regard to race, class, gender, disability, etc.) and with the equitable distribution of health and health care services across populations.

As an ethical principle, justice is not only relevant to individuals; it should also be applied to communities. Community justice "insists on respect for the meanings and values that diverse communities create and hold dear." Therefore, "[c]ommunity justice

Table 1.1 Principlist Biomedical Ethics

Autonomy	Respect for persons. Humans are a means unto themselves and not a means to an end. This encompesses the right to be free to make choices about your body.
Beneficence	Obligation to contribute to person's welfare. Interventions and provisions should provide benefit directly to the patient. This focuses on doing things that are of benefit to another. It requires positive steps to help, and not merely avoiding doing harm.
Nonmaleficence	Obligation not to inflict harm on other persons. Harm is to be avoided or minimized. Underlying tenet of medical professional mission statements (Hippocratic oath).
Justice	For health care, this is the distribution of health (and health care) in a fair and equitable manner. This requires attention to prioritization and rationing. There is no one just way to allocate resources, and most systems utilize several prioritization schemes in concert to attempt to achieve a just distribution.

- **The four principles are meant to be used in concert with each other and not in isolation. To use them one aims to uphold ALL of the principles for any issue. If one or more are violated, the violation needs to be minimal. Additionally, there is no hierarchy of principles—which principle is most important (or which two or three) is dependent on the context of the dilemma.**
- Principlist moral theory can be problematic in that there is no guidance for proceeding when the four principles cannot be balanced (or upheld). It also considers ONLY the four principles, although there are many other principles, considerations, and values to be considered and weighed into decision-making in most ethical dilemmas.
- In Western nations, such as the United States, autonomy tends to have a higher emphasis than in many other places.

DiNardo M, et al. Principlism and Personalism. Comparing Two Ethical Models Applied Clinically in Neonates Undergoing Extracorporeal Membrane Oxygenation Support. Frontiers in Pediatrics. July 30, 2019.

does not describe in a fine-grained way what just [health and] health care would look like; rather it articulates standards or norms required for reaching agreed-to understandings of health and health care that are needed for the provision of just health care services" and community health.[10] In addition, critics have noted that bioethicists often fail to account for social context: "[B]ioethics tends to view the patient or research subject generically, without attention to race, gender, or insurance status…, and, thus bioethics has traditionally adopted rules and has applied them with little, if any, concern for how race or other characteristics affect the working of the rules."[11] The notion of justice in bioethics, therefore, necessarily raises important questions about the ways in which medicine has historically and continues to treat marginalized and vulnerable populations. Concepts of justice—as they relate to health care access as well as to the fair and equitable opportunity to be healthy—are analyzed throughout this text.

Public Health

Frameworks and Definitions

Public health focuses on the promotion and protection of the health of populations. "This work is achieved by promoting healthy lifestyles, researching disease and injury prevention, and detecting, preventing and responding to infectious diseases."[12] In promoting the health of populations, a core question for public health is how to define the term *population*. In the case of the COVID-19 pandemic, public health researchers and practitioners may define the population as all of the people in the world. On the other end of the spectrum, a small rural community may identify a population of 100 or fewer people for the purposes of public health research or testing an intervention to prevent or treat disease. Often, public health researchers and practitioners define a population by a specific category, such as people having a particular disease or people from a certain racial, ethnic, or socioeconomic group. Public health's focus on populations has traditionally been what has distinguished it from medicine. But as noted previously, medicine is increasingly concerning itself with the broader social drivers of health through the perspective of "population medicine."

Nonetheless, public health has long been concerned with the social-ecological model of health that describes the individual, social, socioeconomic, cultural, and environmental factors and conditions that affect the health of individuals and populations and that distribute health inequitably. See **Figure 1.2**.

Goals and Values

At its core, public health is focused on the prevention of disease and injury. The impact of public health actions on population health varies based on the degree to which these actions change the social environment and how much effort is required of individuals. See **Figure 1.3**. The term *upstream* is often used

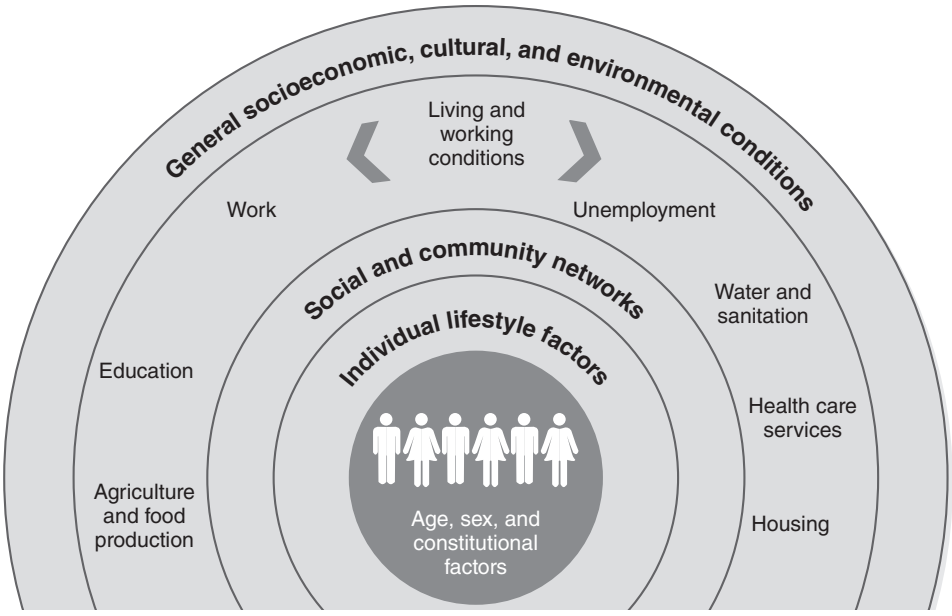

Figure 1.2 The social-ecological model of health

Reproduced from Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. Stockholm Institute for Future Studies;1991.

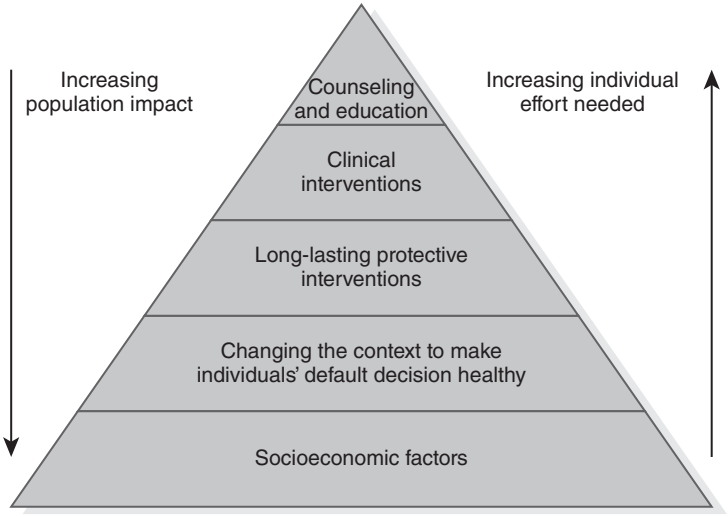

Figure 1.3 The health impact pyramid

Reproduced from Frieden, T.R. A framework for public health action: The health impact pyramid. *American Journal of Public Health.* 2010; 100 (4), 590–595.

to describe interventions that address harmful social and structural drivers that, if avoided, prevent *downstream* disease and injury.

As the field of public health has grappled with the entrenched health disparities evident in America, it has increasingly embraced equity as a core goal. This is clear from the Centers for Disease Control and Prevention's (CDC) recently updated 10 *Essential Public Health Services*. See **Figure 1.4**. As you can see, the 10 services, which include the broader categories of policy development, assurance, and assessment, surround a core value: equity. The original 1994 version of the 10 essential services surrounded the core tool of research.[13]

Public health's attention to the social and structural drivers of health inequity builds on the theory of *social epidemiology*, which "assumes that the distribution of health and disease in a society reflects the distribution of advantages and disadvantages in that society. Based on this premise, social epidemiology examines which sociostructural factors affect the distribution of health and disease, as well as how these factors influence individual and population health."[14]

The theory that public health encompasses a wide range of "conceptual, methodological, scientific, political and moral factors recognizing the interdependency and interrelationship of the health of people, communities, and nations" is articulated in what has been deemed the *new public health,* which promotes "an integrative approach to protecting and promoting the health status of both the individual and the society."[15] The new public health promotes interdisciplinary and intersectoral approaches, including law and policy reform, as important means to addressing the root causes of poor population health and health inequities. The "health in all policies" (HIA) approach is an example of an intersectoral *new* public health strategy. It considers the population health implications of a broad range of policies, such as education, transportation, and housing. Chapter 15 describes HIA in greater detail.

Public Health Ethics

Ethical principles in public health are intended to guide decision-making by public health

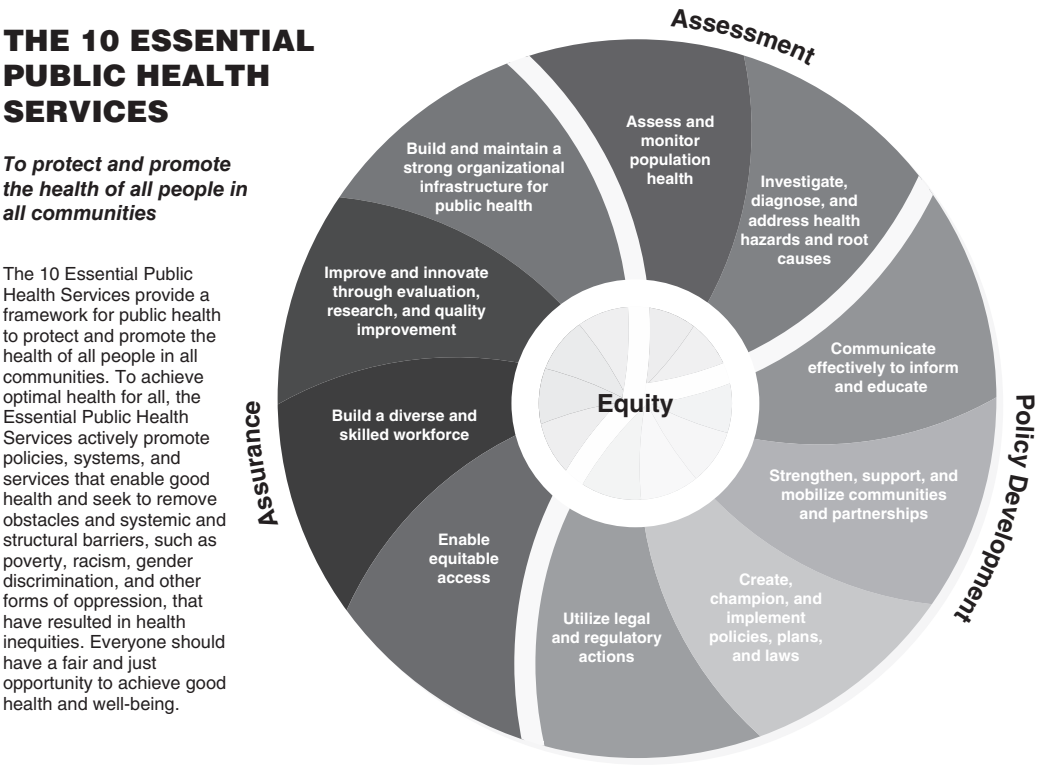

Figure 1.4 The 10 essential public health services

Centers for Disease Control and Prevention. Ten Essential Public Health Services. 2020. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html.

officials and policymakers to ensure that competing interests are carefully acknowledged and weighed before action is taken. Federal, state, and local public health officials carry significant authority to regulate a wide range of business, community, and individual behaviors in order to promote and protect public health, as you will read in Chapter 3. Ethical principles for public health intervention and policy articulate the values of the public health field. For example, the American Public Health Association's 2019 Code of Ethics demonstrate the field's commitment to transparency and public trust; policies and practices that reflect scientific evidence; equity; inclusivity; respect for individual rights; and promotion of communal interests.

As has been apparent throughout the COVID-19 pandemic, balancing all of these ethical principles in public health decision-making, especially during a time of crisis, is extremely fraught. Currently in the United States, ethical decision-making in public health is complicated by political polarization, scientific uncertainty, competing messages from traditional and social media, and general distrust by the public of government authority and institutions.

Law

Frameworks and Definitions

Law as a discipline is broad and diverse. Here, we describe the essential role of law in organizing society and governing human relationships and conduct and also how law relates to health. To begin, we offer a definition of law from *Black's Law Dictionary*:

> That which is laid down, ordained, or established. A rule or method according to which phenomena or actions co-exist or follow each other. Law, in its generic sense, is a body of rules of action or conduct prescribed by controlling authority, and having binding legal force. That which must be obeyed and followed by citizens subject to sanctions or legal consequences is a law.[16]

But law is more than rules. Law reflects the evolving customs, beliefs, and value systems of a given nation, state, or locality. Indeed, law "takes an understanding, a norm, an attitude, and hardens it into muscle and bone."[17] It reaches into nearly every corner of American life. People encounter laws daily pertaining to the environment, property ownership, the workplace, civil rights, copyright, energy, banking, and much more. Hence, a society as sprawling and complex as ours needs formal, enforceable rules of law to provide a measure of control (for example, the need to regulate entities or actions that are potentially dangerous or invidious—a polluting power plant or acts of discrimination based on race or gender). Law is also expected to achieve "justice" by producing outcomes based on fairness and equality. The legal system in the United States encompasses the complex interactions among the three branches of government (legislative, executive, and judicial) charged with writing, implementing, and interpreting the law, as discussed in detail in Chapter 3.

Law relates to medicine and public health in multiple and distinct ways. Traditionally, the law of medicine or what is typically called *health care law* has been understood as the rules and regulations governing the health care industry, including hospitals and other health care organizations and providers, insurers, and pharmaceutical and device manufacturers, as well as individual medical professionals. Health care laws include, among many others, antitrust laws governing hospital system mergers, medical fraud and abuse by providers and insurers, medical malpractice, and privacy laws such as the Health Insurance Portability and Accountability Act (HIPAA). As discussed later, in recent years, the definition of health care law has been expanded to incorporate a broader range of laws that implicate health equity and justice. Furthermore, the field of public health law utilizes a definition that is distinct from health care law. Consider scholar Lawrence Gostin's definition of public health law:

> Public health law is the study of the legal powers and duties of the state, in collaboration with its partners (e.g., health care, business, the community, the media, and academe), to assure the conditions for people to be healthy (to identify, prevent, and ameliorate risks to health in the population) and the limitations on the power of the state to constrain the autonomy, privacy, liberty, proprietary, or other legally protected interests of individuals for the common good. The prime objective of public health law is to pursue the highest possible level of physical and mental health in the population, consistent with the values of social justice.

In addition to regulating the actions of stakeholders in the medical care system and defining the duties and limits of public health authority, law plays a vital role in structuring the conditions in which people live. In so doing, law is an important social driver of health. It governs physical environments, such as through laws regulating environmental hazards, workplace safety, and rental property standards. It also shapes social environments and norms through laws that, for example, regulate smoking, tax sugar-sweetened beverages, and require restaurants to publish

calorie counts on their menus. Perhaps most importantly, it structures the distribution of resources needed for people to be and stay healthy, including through tax laws, health care policies, and regulations structuring and governing safety net programs.[18]

Values and Goals

With greater attention to the many ways in which law shapes health outcomes and inequities, health care law and public health law scholars and practitioners are redefining the goals and values of law and legal practice. They are also finding common ground in recognizing the upstream role that law plays in both individual and population health, thus implicating both medicine and public health. As medical professionals confront the downstream effects of failed social policies in meeting patients' unmet social needs, they are acknowledging the critical role that law plays in shaping not only the medical care and public health systems but also their patients' health potential. Medical-legal partnerships are offering opportunities for lawyers and medical teams to work together to aid patients not only in enforcing legal rights that affect their health but also in jointly advocating for legal and policy changes that promote and support health, as discussed in Chapter 15.

Similarly, public health professionals and practitioners are joining forces with lawyers to identify ways to employ law as a tool to promote and protect health, including through addressing social drivers of health. Public health lawyers are also studying how specific laws—as written and as implemented and enforced—affect the health of the people subject to those laws. This approach is called *legal epidemiology*, defined as "the scientific study and use of law as a factor in the cause, distribution, and prevention of disease and injury in a population." This empirical approach helps public health officials and public health lawyers to better understand "*how* law influences health…and *whether* it does so."[19] As interdisciplinary approaches to health care law and public health law take hold, they share two values and goals: improving and promoting individual and population health in the United States and eliminating the health inequities that have plagued this country for so long.

Ethics

Legal ethics are generally understood as the professional rules of conduct for lawyers. Lawyers are governed by state ethics rules that address issues such as the lawyer-client relationship, the lawyer's duty to serve as a zealous advocate for the client, client confidentiality, conflicts of interest, and professional independence. The legal profession highly values lawyers' duties to their clients above all else. Strict ethical rules for lawyers can sometimes make interdisciplinary collaboration with other professionals, such as medical and public health professionals, difficult. For example, a lawyer working with medical professionals to assist a patient with a legal barrier to health—such as the risk of an eviction from the patient's home—may only share information with a medical team if the patient/client permits it. Increasingly, medical-legal partnerships and other interdisciplinary collaborations are finding effective ways to protect patients' rights while also engaging in collaborative problem-solving without running afoul of professional ethical rules.[20]

Lawyers in public health agencies or those working collaboratively with public health partners must also be mindful of ethical rules guiding their behavior. They must balance duty to their client and fidelity to existing law and its limits with their partners' broader public health goals. This may mean that they must sometimes advise a more measured approach to public intervention or action than their colleagues are seeking. Nonetheless, working in tandem with public health colleagues, lawyers often find innovative ways to use the law as a tool for prevention and for promoting public health. As medical, public health, and legal professionals apply intersectoral approaches to population health improvement and equity, they are reimagining their professional boundaries and developing innovative approaches and

strategies to health justice. We explore these approaches and strategies in later chapters.

Critical Theories: Challenging Norms and Shaping Definitions of Health Justice

With that overview of the fields of medicine, public health, and law, we now turn to discussion of some of the critical theories driving discourse around inequality, marginalization, and power in the United States. We present these theories to challenge you to think about how norms shaped by dominant power structures serve to control not only the distribution of opportunities and resources but also whose voices are heard and valued. Here we focus on critical race, feminist, queer, and disability theories. We begin each topic with some definitions. In presenting these definitions, we acknowledge that readers may disagree with our choices and language. Language, after all, is powerful: It shapes norms, creates mental images that are inclusive or exclusive, and either reinforces or disrupts biases. We challenge you to critique our language and definitions as you think critically about what health justice means or should mean in the future. After presenting definitions and theories, we explore the ways in which these critical theories apply to medicine, public health, and law.

Race and Ethnicity

Definitions of race and ethnicity are far from static. In the areas of medicine and public health, definitions of race and ethnicity have profound implications for the health of People of Color and for approaches to addressing health inequities. Historically (and still in some circles today), race has been defined as a biological category. Biological notions of race have been used to justify health inequities and perpetuate notions of White superiority. The way race is defined in the law shapes legal responses to discrimination and racism and structures the obligations of governmental officials to address injustices. We start with definitions to delineate the different ways in which race and racism have been construed in the past and how they are being redefined. We then explore critical race theory, which confronts how definitions of race and racism have been used by those in power to categorize and subjugate people based on their assigned race and/or ethnicity.

Definitions

Race is a social construct that artificially categorizes people by phenotype—"the societal box into which others put you based on your physical features."[21] The United States has a disturbing history with regard to racial classification, given how much those classifications have been infused with bigoted beliefs about White superiority. Therefore, race is a "harmful way to think about human biological differences."[22] From a scientific perspective, racial taxonomy is inadequate because "(1) the concept of race is based on the idea of fixed, ideal, and unchanging types; (2) human variation is continuous; (3) human variation is nonconcordant; (4) within-group genetic variation is much greater than variation among 'races'; (5) there is no way to consistently classify by race; and (6) there is no clarity as to what race is and what it is not."[23] As legal scholar Dorothy Roberts notes, race is not just a social construct, it is a "political category that is defined by invented rules"[24] that have profound consequences for "people's health, wealth, social status, reputation, and opportunities in life."[25]

Ethnicity is a social construct that sorts people into groups based on common national and/or cultural traditions, language, sense of group membership, or values.[26] At times in American history, ethnicity has been equated with race. For example, until the 1970s, Mexicans were classified in the Census simply as "White." Then, in the 1980s, the Census included the word *Hispanic*, which was later changed in the 2000 Census to *Latino*.[27]

Assigned ethnicity may or may not correspond to how people identify themselves.

Racism is the combination of racial prejudice (a prejudgment about a person or group based on negative stereotypes) and the power to subordinate people based on their assigned "race." Racism "is a system of structuring opportunity and assigning value based on phenotype (race) that: unfairly disadvantages some individuals and communities; unfairly advantages other individuals and communities; [and] undermines realization of the full potential of the whole society through the waste of human resources."[28] Racism can operate at various levels, including (1) interpersonal racism, or experiences of discrimination and prejudice experienced in everyday life; (2) internalized racism, in which victims of racism internalize prejudicial attitudes resulting in stress or loss of self-esteem; and (3) structural and institutionalized racism, which are "the structural elements of racism that are codified in our institutions of customs, practice and law so there need not be an identifiable perpetrator."[29]

Critical Race Theory

Critical race theory (CRT) developed in the 1970s and 1980s post–civil rights era at a time when the "prevailing sense was that the law was not at all involved in creating and sustaining racial hierarchies."[30] Law professor Derrick Bell, one of the founders of CRT, argued that the persistence of racial inequality in the post–civil rights era resulted in part from the failure of civil rights laws to fundamentally address racial injustice. His scholarship focused on interrogating the ways in which law continued to both construct and justify racial inequality. He argued that American institutions, either intentionally or unintentionally, justify or minimize racism.[31] Kimberlé Crenshaw, who coined the term *critical race theory*, has acknowledged that CRT is "fundamentally eclectic" and is "not a fully unified school of thought."[32] Instead, she says, it is a framework for interrogating racial hierarchy and inequality. Indeed, "the scholars who produce CRT are an interdisciplinary bunch, and they bring a broad range of investigative tools—including anthropology, history, qualitative and quantitative sociology, political theory, and economics, among others—to bear in their inquiries."[33] (As discussed later, CRT has been applied not just to law but also to medicine and public health and has been an important tool for analyzing the connections between racial inequality and health injustice.)

According to legal scholar Khiara Bridges, there are four basic tenets that animate CRT: First is the understanding that race is not biological; it is a social construct (as noted previously). CRT scholars argue that, while race is not a biologic reality, the *social* reality must be analyzed in terms of how racial classification affects the lives of People of Color. Second, racism is a foundational part of American society. Bell argued that racism runs through and is reinforced by all U.S. institutions. Therefore, racist incidents (e.g., recurring events of police brutality in Communities of Color) are not aberrations, but rather are indicative of structural/institutionalized racism. Third, CRT rejects the idea that racism is equated with race consciousness. Scholars argue that "colorblindness" not only papers over structural racism, it makes remediation for past harms impossible. For example, Supreme Court decisions that employ colorblindness and that make racial discrimination only actionable with proof of intentional discrimination have severely hindered racial justice, as touched on in Chapter 6. Fourth, CRT privileges the lived experiences of People of Color as critical to scholarly analysis (i.e., scholarship is only valuable if it contributes to dismantling racial oppression and improves the lives of real people).[34]

Equality Versus Equity. Arguing that racism is deeply embedded in the fabric of American law, systems, and institutions, CRT scholars assert that remedies for racial injustice must be based on the principle of equity. They contend that it is not sufficient to assume that all racial groups have equal

opportunities (e.g., educational and economic) when the legacy of legalized racial discrimination and structural racism continue to disproportionately limit the opportunities of certain racial and ethnic groups. They assert that *equity* (as opposed to *equality)* demands that policies allocating the distribution of resources (e.g., taxes, public benefits, health care, housing) acknowledge past discrimination, structural racism, and power differentials. Thus, equitable policies should focus on what historically marginalized people actually need in order to have the opportunity to achieve their full potential.

Interest Convergence. Some CRT scholars have argued that "the interests of blacks in achieving racial equality have been accommodated only when they have converged with the interests of powerful whites."[35] Derrick Bell described this "interest convergence" to help explain why, even after passage of civil rights laws, racial injustice continues. Writing about *Brown v. Board of Education*, the Supreme Court decision holding racially segregated schools unconstitutional, Bell says the Court's decision "cannot be understood without some consideration of the decision's value to whites, not simply those concerned about the immorality of racial inequality, but also those whites in policymaking positions able to see the economic and political advances at home and abroad that would follow abandonment of segregation."[36] Specifically, he pointed out that during the Cold War, the hypocrisy of America's racial segregation made it look bad to the rest of the world. Additionally, policymakers feared that the communist movement was gaining support among some in the Black community because racial minorities were treated better in some communist countries than they were in the United States. However, he noted, the promise of equal educational opportunity did not materialize for most Black children, as schools remain as racially segregated today as they were before the Civil Rights Movement.[37] Thus, Bell suggests that as long as racial equality threatens the interests of privileged White people, change will not occur.[38]

Intersectionality. CRT legal scholar Kimberlé Crenshaw first coined the term *intersectionality* in 1989 to articulate the legal "Catch-22" that Black women experienced when alleging employment discrimination. Under most courts' interpretation of employment discrimination law, Women of Color are forced to choose whether to allege that they are being discriminated against because of their race or their gender but not both. Instead of acknowledging that Women of Color have more than one identity (e.g., racial, ethnic, sex, gender identity) affecting their status in society, they are boxed into selecting one over another. Crenshaw explains that "[i]ntersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects. It's not simply that there's a race problem here, a gender problem here, and a class or LBGTQ problem there. Many times that framework erases what happens to people who are subject to all of these things."[39] (Later we discuss how Crenshaw's theory of intersectionality has been applied through other critical theories and also its relevance for health justice.)

Application of Critical Race Theory and Intersectionality to Medicine, Public Health, and Law

Medicine

CRT theorists critique the notion that racism is only present in medicine when there is overt individual discrimination that occurs in interactions between health care providers and patients. While they acknowledge that interpersonal racism is a problem in medicine, they focus on the ways in which racism is deeply imbedded and institutionalized in medical science and medical practice through the misuse

of race as a biological category.[40] Historically, the medical and scientific communities have employed biological race as a means to reinforce racial hierarchies.[41] Bogus theories of genetic differences based on race fueled the eugenics movement (which had as its goal the elimination of undesirable genetic traits in human beings, often associated with race)[42] and the Bell Curve intelligence theory (the idea that IQ is associated with race),[43] and they continue to influence understandings of race in medicine.[44]

Science has disproven genetic theories of race. Indeed, 99.9% of the genetic makeup of human beings is identical and the 0.1% variation among them is not associated with any racial grouping.[45] However, despite this evidence, the use of biological or genetic race has not disappeared from medical research or guidelines. A 2021 article in the *Journal of the American Medical Association* asserts that:

> [R]ace variables have become part of the norm of accepted medical knowledge and practice. This applies to both therapeutics (incorporation of race to identify clinically meaningful treatment effect modification for various interventions, as in hypertension or heart failure) and other clinical tools (incorporation of race to improve diagnosis or prognosis in, for example, calculation of kidney function or pulmonary function).[46]

Using race when diagnosing and treating patients gives rise to pseudo-biological explanations for health inequities. CRT scholars continue to challenge references to biological race in medicine as the underlying cause of health inequities and instead insist that researchers identify and call out how racism is the root cause of these inequities.

Public Health

Public health scholars have also embraced CRT as a way to identify and investigate how structural racism infects health. Public health scholars Chandra Ford and Collins Airhihenbuwa point out that CRT is useful as a way to critique racial bias in public health research: "Racism was rarely considered an important determinant of health. The introduction of CRT for empirical research helps address these concerns directly. Its tools help researchers illuminate racial biases embedded in a field or in a study's aims, methods, conclusions, etc., and develop strategies to address them."[47] To help public health researchers and practitioners incorporate the tools of CRT inquiry, they developed public health critical race praxis (PHCR). PHCR is a framework for health equity research that "examines the causes of racial/ethnic patterns of health and disease" and interrogates "the racial context in which the research is conducted."[48]

Law

CRT was born out of critical legal studies theory, which challenged the "objectivity and neutrality of the law."[49] Legal scholar Roy L. Brooks articulates the goals of CRT in law as:

> attempt[ing] to analyze law and legal traditions through the history, contemporary experiences and racial sensibilities of racial minorities in this country. The question always lurking in the background of CRT is this: What would the legal landscape look like today if people of color were the decision-makers?[50]

CRT scholars note that, because law is primarily concerned with resolving individual disputes—such as employment discrimination—it leaves in place the structural underpinnings of inequality and disadvantage. However, they also recognize that law can be used as "a tool for emancipation and for securing racial equality."[51] Thus, CRT legal scholars ask these types of questions: How does the law construct race? How has the law protected racism and

upheld racial hierarchies? How does the law reproduce racial inequality? How can the law be used to dismantle race, racism, and racial inequality? The law's treatment of racism and racial discrimination has played a major role in perpetuating health injustice, as discussed in Chapter 6.

Sex and Gender

Understandings of sex, gender, and sexuality continue to evolve. Following we offer some initial definitions. (A more extensive glossary of terms is provided in Chapter 13.) We then turn to how definitions of sex, gender, and sexuality have been influenced and transformed by social and political theories that subvert underlying assumptions about what it means to be "male" and "female." Feminist and queer theories both challenge the extant power structures (including the language and definitions that sustain them) that subordinate people based on their sex and/or gender and sexuality.

Definitions[52]

Sex is the sex (male or female) assigned to an infant, most often based on the infant's anatomical and other biological characteristics. In law, the term *sex* may include gender identity and sexual orientation status.

Sexism describes bias and discrimination against a person based on their sex or gender. Like racism, there are interpersonal, internalized, and structural levels of sexism. Sexism most affects women and LGBTQ+ people, but it also can also affect cisgender men, who are expected to conform to societal expectations of masculinity.

Gender is the characteristics and roles of women and men according to social norms. While sex is described as female, male, and intersex, gender can be described as feminine, masculine, androgynous, and many more.

Gender identity is a person's inner sense of being a girl/woman/female, boy/man/male, something else, or having no gender.

Cisgender describes a person whose gender identity is consistent in a traditional sense with their sex assigned at birth—for example, a person assigned female sex at birth whose gender identity is woman/female.

Gay is a sexual orientation describing people who are primarily emotionally and physically attracted to people of the same sex and/or gender as themselves. Commonly used to describe men who are primarily attracted to men but can also describe women attracted to women.

Feminism/Feminist. Definitions of "feminism" and what it means to be a "feminist" have varied over time and across different countries and cultures. Feminism is generally understood as the belief in and commitment to social, economic, and political equality for all people regardless of sex or gender. A feminist is a person who advocates for equal rights for all people regardless of sex or gender.

Heteronormativity is the assumption that everyone is heterosexual or that only heterosexuality is "normal." It also refers to societal pressure for everyone to look and act in a stereotypically heterosexual way. Heteronormativity can manifest as heterosexism, the biased belief that heterosexuality is superior to all other sexualities.

LGBTQ+ stands for lesbian, gay, bisexual, transgender, queer, and other persons whose sexual orientation or gender identity falls outside societal norms.

Nonbinary describes a person whose gender identity falls outside the traditional gender binary structure of girl/woman and boy/man. Sometimes abbreviated as NB or enby.

Queer is an umbrella term describing people who think of their sexual orientation or gender identity as outside societal norms.

Sexual orientation is how a person characterizes their emotional and sexual attraction to others.

Transgender describes a person whose gender identity and sex assigned at birth do not correspond based on traditional expectations—for example, a person assigned female sex at birth who identifies as a man or a person

assigned male sex at birth who identifies as a woman.

Woman is a person who identifies as female regardless of the person's sex assigned at birth.

Feminist Theory

Feminist theory continues to evolve over time and has been shaped by historical, political and cultural contexts. The feminist or women's movement in the United States has had many iterations, as we discuss in more detail in Chapter 2. Nonetheless, feminist theory can be described as "the range of committed inquiry and activity dedicated first, to describing women's subordination—exploring its nature and extent; dedicated second, to asking both how—through what mechanisms, and why—for what complex and interwoven reasons—women continue to occupy that position; and dedicated third, to change."[53] "Inquiry and activity" in feminist theory centers on several themes that are relevant to gender inequity in medicine, public health, and law. We describe these in the following sections.

The Private Versus Public Spheres. Feminist theory challenges traditional social role divisions that assign women to the "private sphere" (e.g., responsibility for housework, child care, and eldercare) and provide men greater access to the public sphere (e.g., paid work, politics, business). Feminist theorists have challenged this dichotomy and critiqued the ways in which it structures and maintains male power and female subordination. They call for the full participation of women in society's social, economic, and political spheres equal to that of men; they also call for men to share equal responsibility for domestic responsibilities, arguing that this is both fair and better for families and society.

Equality Versus Difference. Feminists' call for full equality between men and women in all aspects of society has been met with resistance based on two claims: Men and women are biologically different and therefore should be treated differently in some contexts (e.g., military service), and women may have different preferences and make different choices than men (e.g., the idea that women are more inclined toward child care than are men). In essence, this argument is that gender inequity is the result of nature (biological difference) and choice (women want different things than men), not unequal power differentials between men and women. Feminist theorists have grappled with the *equality versus difference dilemma*, which asks: Should women try to conform to male standards of behavior in order to obtain full equality with them, or should they embrace notions of women's differences from men (e.g., the idea that women are more interested in relationships and caretaking than are men)? This question requires a deeper interrogation of the role of biology in constructing differences between men and women versus the role of social structures in constructing them.

The Male Norm. As women have sought power in the workplace, politics, and other seats of power and privilege, the equality versus difference dilemma has required feminist theorists to uncover and expose the ways in which systems (including health care and public health systems), laws, and policies have been constructed around a male norm. Indeed, the notion that women were somehow defective versions of men took root as early as the third century BC when the philosopher Aristotle described the female as a "deformed male."[54] Feminist critiques have extended from biblical references to women's bodies being molded out of the male model (Adam and Eve) to demonstrating how ostensibly neutral rules and practices ignore women's experiences and are formulated with men in mind. Feminist legal scholar Catherine McKinnon explained that societal norms have been largely built around a male model: "Men's physiology defines most sports, their needs define auto and health insurance coverage, their socially designed biographies define workplace expectations and successful career patterns, their

perspectives and concerns define quality in scholarship, their objectification of life defines art…."[55]

In the 1980s, feminist theorists began to redefine the quest for equality, rejecting the idea that women should have to conform to a (traditional) male role in order to be treated equally. Instead, they argued that when women differed from men (e.g., in the ability to become pregnant), society, law, and policy should change to accommodate women, not the other way around. This shift led to feminists asserting the ways in which women's experiences were different from those of men and demonstrating how women's experiences have been devalued and deprioritized by society.

The Female Body. Early philosophers viewed women as lacking the rationality required for public discourse and public life. Instead, they associated women with emotion, nature, the body, and reproduction.[56] This association has often been used to justify women's domestic role, as they were seen as too irrational (based on their deep connection to nature resulting from menstruation and childbirth) to participate in public life. Feminist critics have not only rejected assumptions about women as less rational, they have confronted the ways in which the female body has been presented and objectified through the dominant male perspective. In particular, they have challenged the historical and contemporary images of women's body in art and media such as "the maternal body, the vulnerable body, the victimized body, the hysterical body, the body with no desire of its own, the regulated body, the rebellious body, the thin body."[57] They call for women to reimagine and represent their own images of the female body in order to reclaim power and self-worth.

Anti-Essentialism and Intersectionality. As feminist theory evolved during the 1970s and 1980s, scholars began to critique the ways in which feminism and the feminist movement were primarily associated with the experiences of White, middle-class, cisgender women, ignoring the diverging experiences of women by race, ethnicity, class, sexual orientation, and gender identity. Feminist scholarship in this area has been most robust in legal studies. Legal scholar Angela Harris coined the term *essentialism* to describe "the notion that a unitary, 'essential' women's experience can be isolated and described independently of race, class, sexual orientation, and other realities of experience."[58] Essentialism, for example, has forced Black women into an either/or dichotomy to explain their oppression (i.e., gender discrimination versus racial discrimination but not both). As discussed earlier, legal scholar Kimberlé Crenshaw instead proposed an "intersectional" approach to understanding the discrimination and subordination based on multiple identities. Applying intersectionality to Black women, for example, acknowledges that they "experience double-discrimination—the combined effects of practices that discriminate on the basis of race and the basis of sex. And sometimes, they experience discrimination as Black women—not the sum of race and sex discrimination, but as Black women."[59] Thus, in feminist theory, an intersectional approach rejects the notion that women should have to check only one box. As discussed later, intersectionality has also been critical to queer theory.

Application of Feminist Theory to Medicine, Public Health, and Law

Medicine

Feminist theory has been applied to medicine in several ways. First, it has been used to challenge the primacy of the male body and men's health in everything from medical research and education to health insurance coverage.[60] Second, because much of medicine has historically ignored women's health, feminists have focused on elevating women's knowledge about their own bodies, symptoms, and health.[61] This includes deconstructing medical myths about

women as inferior due to menstruation, pregnancy, and menopause and empowering them to see their bodies as not only normal but powerful.[62] Third, challenging myths about women's health has been particularly important in countering the historical notion of "hysteria" in medicine—that women's symptoms were a function of their emotions, not real medical problems. Feminists in the medical community note that these stereotypes are still prevalent in medicine today: Women are often told by medical providers that their physical ailments, especially their pain, are "all in their heads."[63] Fourth, feminists have sought to dismantle what they view as the medicalization of women's health, especially control by male doctors of the natural process of childbirth. Instead, they advocate for traditional models of women supporting one another during pregnancy and childbirth, such as through midwifery and doula care. Finally, feminists have promoted equity in the profession of medicine and scientific research, highlighting how women have been historically excluded from and continue to be marginalized in medicine, especially from positions of power.

Public Health

Feminist scholars in public health have similarly sought to disrupt ways of conceptualizing health that have been largely constructed around men by centering research on women's health experiences and developing theoretical frameworks that challenge assumptions based on gender norms. They have explored public health methods that are sensitive to gender differences and the wide diversity within and across genders. Intersectional feminist theory is applied to public health in its growing attention to the complex social drivers of health that call upon multidisciplinary approaches and perspectives. Finally, feminists have supported collective action approaches to structural change by employing an anti-subordination framework to public health problems.[64]

Law

In law, scholars have applied feminist theory to critique the very structures of the law: how gender assumptions influence the development, interpretation, and effect of the law on women and men. These include identifying how biases and discrimination affect women's opportunities (e.g., in the workplace, politics, leadership); illuminating how assumptions based on a male norm devalue women's experiences, voices, and contributions; challenging power structures that reduce or eliminate women's choices; and promoting an intersectional approach that draws on critical race theory and other frameworks for understanding women's subordination. In practical terms, feminist theory is applied to issues such as reproductive rights and caretaking responsibilities, sexual and domestic violence, and women's economic opportunity and subordination. Women's legal rights are vital to health justice, as we discuss rom more detail in Chapter 12.

Queer Theory

Developing out of gay and lesbian studies and women's and feminist studies, queer theory took hold in the 1990s to theorize and describe gender identities and sexuality that do not conform to the heterosexual "norm." Queer theory disrupts essentialist heterosexual and cisgender notions of identity and sexual desire. Thus, "queer theory and politics necessarily celebrate transgression in the form of visible difference from norms. These 'Norms' are then exposed to be norms, not natures or inevitabilities."[65]

Challenging Gender Binaries and Hierarchies. Like feminist theory, which calls into question assumptions about biological differences between men and women and how those assumptions have been employed to subordinate women to men, queer theory interrogates societal and

cultural norms that label people as abnormal based on their sexual orientation and gender identity. Queer theorist Judith Butler challenges traditional feminist theory's static definition of "woman," arguing that in queer theory "the very subject of women is no longer understood in stable or abiding terms."[66] Butler argues that gender—being labeled a man or woman—is essentially a performance based on culturally constructed behaviors (i.e., how people dress, walk, speak, wear their hair) that define maleness or femaleness as though these categories are natural.[67] Indeed, queer theory contests binaries—such as male or female, straight or gay—that simplify and ignore the fluidity of sexuality and gender identities. It also points to the ways in which these binaries are hierarchical, assigning value to some over others (e.g., male over female, straight over gay, cisgender over transgender) to justify disparate treatment.[68]

Questioning Sexual and Gender Norms. Queer theorists also analyze the ways in which science, which is viewed as neutral and objective, has shaped understandings of what is "normal" and "abnormal" in gender identity and behavior, noting that behavioral norms have fluctuated and evolved over time and across cultures. They challenge the ways in which science and medicine have pathologized homosexuality and gender-nonconforming behaviors as diseases, mental illness, and social deviance. (Chapter 13 discusses the history of medical and psychiatric treatment of LGBTQ+ people in detail.) Queer theory also rejects societal expectations that, to avoid the stigma associated with their sexual orientation and gender identity, LGBTQ+ people must hide their true selves (i.e., "staying in the closet"). In this way, queer theory, like feminist theory and CRT, rejects assimilation into the dominant culture and instead calls into question societal (White, male, cisgender) norms themselves.

Intersectionality: The Queer of Color Critique. As with feminist theory, queer theory has expanded to recognize overlapping, multiple identities and how people who are, for example, queer, female-identifying, and Black, confront compounding oppression from homophobia, cisgenderism, sexism, and racism. The queer of color critique decenters the White gay male as the frame of reference for queer theory and embraces an intersectional analysis. In *Unapologetic: A Black Queer and Feminist Mandate for Radical Movements*, Charlene Carruthers describes a queer of color critique as "a political praxis (practice and theory) based in Black feminist and LGBTQ traditions and knowledge, through which people and groups see to bring their full selves into the process of dismantling all systems of oppression."[69]

Application of Queer Theory to Medicine, Public Health, and Law

Medicine

Queer theory critiques medicine and medical treatment in at least three ways. First, queer theorists deconstruct the historical (and often current) treatment of LGBTQ+ people as deviating from the norm in their sexuality and gender identities. Queer theory rejects medicine's categorization of people's sex, sexuality, and gender into hierarchical binaries—male versus female, sexually normal versus sexually abnormal, and healthy gender-conforming versus unhealthy gender-deviant. Queer theorists and activists ask the medical community to recognize and honor gender diversity and fluidity. Second, they challenge how medical and other health professions education reinforces heteronormativity and binary approaches to gender not only by failing to acknowledge the spectrum of gender identities but also by reproducing gender subordination in failing to teach future physicians about LGBTQ+-affirming care. Third, queer theory supports structural changes to health care that

support dignified and safe spaces for the care of LGBTQ+ patients. Queer theory demands that the medical community engage in "further analysis into the contradictions between the urgency of ethical biomedical practice and critical healing alongside the various discourses, ideologies, and cultures which shape biomedicine, and by which biomedical knowledge and clinical practices are themselves shaped."[70]

Public Health

Queer theory has been applied to public health by promoting an intersectional and intersectoral understanding of and approach to gender and health. In addition to calling for restructuring health education and health care, queer theorists articulate and critique the multiple social drivers of LGBTQ+ people's health. Recognizing that social drivers, including where people live, work, and go to school, have profound effects on health, theorists demand structural changes that lead to language, education, and spaces that support and affirm LGBTQ+ people in all aspects of their lives. These changes include using inclusive, nonbinary language; promoting sex education that is not heteronormative; and creating nonbinary public spaces, such as bathrooms. These societal changes, they argue, will improve public health by reducing stigma that is health-harming to LGBTQ+ people. Queer theory also critiques public health research that is not inclusive of gender-nonconforming people and promotes research that challenges normative assumptions about gender but also supports better health for LGBTQ+ populations.[71] This would mean, for example, designing research studies that divide people not by male/female but instead by subpopulations based on research subjects' gender identities.

Law

Queer legal theory interrogates the way in which law normalizes and sustains the subordination of LGBTQ+ people based on privileging heteronormative notions of sex, sexuality, and gender. Since America continues to permit legalized discrimination against LGBTQ+ people, many queer legal scholars focus on challenging overtly discriminatory laws, such as those in employment, housing, and education. But like feminist theorists, queer legal theorists have struggled with the ways in which concepts such as "equality" may, on the one hand, lead to expanded legal rights for LGBTQ+ people but, on the other hand, reinforce the requirement that they assimilate to heteronormative expectations and behavior in order to obtain legal rights and status. For example, some queer theorists have critiqued the focus on legalizing marriage equality for gays and lesbians as embracing a patriarchal heterosexual norm in order to pursue state recognition. Thus, queer legal theory involves a "reflexive and ongoing engagement with legal issues around sex, gender and sexuality that sit at the nexus of power and knowledge."[72]

Disability

Disability studies as a unique field of study began in the United States in the late 1960s as part of the disability rights movement. As disability scholars Rabia Belt and Doron Dorfman explain, advocates "challenged ableist assumptions about their existence and catalyzed the still-evolving academic field of disability studies…[which] concerns itself with human difference and the ways people with disabilities have been pushed out of what society conceives as the 'normal.' The critique of normalcy as a socially constructed category has thus been a cornerstone in the field."[73] Defining what is meant by *disability* has profound medical, social, legal, and political implications for people determined to be *disabled*. Critical disability theory developed out of disability studies as a method to "scrutinize[e] not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate

stigmatized attributes in particular populations."[74] We explore the evolution of definitions of disability and the ways in which critical disability theory seeks to empower people with disabilities to define themselves.

Definitions

Ableism is "[the] negative rating of a person's abilities and productivity based on assumptions about that person's capabilities as assessed by non-disabled people. Ableism encompasses deeply held beliefs about productivity, attractiveness, and the value of human life."[75]

Disability. We begin with the definition of disability used by the World Health Organization, acknowledging that disability theorists and activists take issue with it. We do so to introduce some of the terminology (*impairment*, *activity limitation*) that is often used to describe disability. Following we will highlight the evolution of different definitions of disability. The WHO describes three dimensions of disability:

1. **Impairment** in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision, or memory loss
2. **Activity limitation**, such as difficulty seeing, hearing, walking, or problem solving
3. **Participation restrictions** in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services[76]

Critical Disability Theory

Critical disability theory shares common ground with critical race theory, feminist theory, and queer theory in that it probes "basic assumptions about identity, ideology, politics, meaning, social justice and the body."[77] Like other critical theories, disability theory is employed to resist static definitions of disability in favor of evolving understanding of what it means to be disabled, driven by disabled people themselves. It is also political in that "scrutiny of normative ideologies should occur not for its own sake but with the goal of producing knowledge in support of justice for people with stigmatized bodies and minds."[78] Here we consider the medical and social models of disability and how critical disability theorists have critiqued these models with an eye toward social and health justice for people with disabilities.

The Medical Model of Disability. In some ways, the medical model of disability has been driven by the status and authority that medical professionals have in diagnosing illness and defining bodily, cognitive, or psychiatric impairment. The medical model seeks to "fix" disability to the extent possible through a biomedical cure or remedy. From the perspective of critical disability theory, the medical model begins with the assumption that the "problem" begins with the patient, who is somehow faulty. Thus, the medical model is normative in that it compares the disabled person to the so-called "normal person." Under the medical model, disabled people are viewed as unable to care for themselves and in need of charity, relying on clinicians to define and categorize their disability and to determine their needs and rights, including access to certain government supports and legal protection from discrimination. Thus, the medical model is viewed as a deficit-based approach to disability in which disabled people are defined by their disability without regard to how they define themselves, their needs, and their wants.[79]

Social Model of Disability. The social model of disability developed as part of the disability studies movement in response to critiques of the medical model of disability. Rather than centering the individual's impairment as the site of the problem, the social model focuses on the ways in which disability is socially constructed by

societal norms, attitudes, laws, and policies. The social model divorces impairment from disability in order to focus on how society excludes, disadvantages, and erects barriers for disabled people. The isolation and exclusion of disabled people, therefore, are viewed as the result of societal choices and the unwillingness by those holding power to construct and organize the social world with disabled people in mind.[80]

Crip Theory. Building on other critical theories, crip theory contests centers of power to probe how definitions of disability act to subordinate, marginalize, and stigmatize people with disabilities. Just as queer theory inverted the meaning of *queer*, an epithet, to a term embracing gender diversity, disability theorists and activists appropriated the term *crip* (a version of the derogatory word *crippled*) to define disability as an identity and as "life enriching and contributing to human diversity."[81] Crip theory contests the dominant deficit-based view of disability and privileging of ableism, instead centering the perspectives of disabled people in order to conceptualize their own identities and futures. It also critiques the ways in which capitalism and its ableist approach to work, economic, and social value define power in society. Finally, it fully embraces an intersectional understanding of disability, sexuality, and gender identity and probes questions related the connections between racial, ethnic, and disability discrimination.[82]

Application of Critical Disability Theory to Medicine, Public Health, and Law

Medicine

As discussed previously, critical disability theory rejects the medicalization of disability, instead pointing to its social construction. It has sought to give disabled people voice in making their own decisions about how they wish to live and how they construct their identities, apart from medical interference and paternalism. Indeed, "disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to."[83] On the other hand, in recent years some critical disability theorists and activists have criticized the social model in failing to fully recognize and address the very real medical needs of disabled people, including the pain and mental stress associated with impairment, divorced from social stigma and treatment. They point out that only focusing on social discrimination may undermine important efforts to ensure disabled people obtain appropriate, accessible, and respectful health care.[84] Furthermore, like critical race, feminist, and queer theories, critical disability theorists and activists call for better training for clinicians so that medical professionals are forced to confront their own biases about disability and so that disabled patients are empowered through shared decision-making and patient-centered models of care.[85]

Public Health

Public health's focus on prevention has sometimes led to an uncomfortable relationship with disability. How can public health embrace disability theory and at the same time maintain its focus on prevention? Increasingly, public health organizations and practitioners are embracing disability theory by advocating for and employing secondary prevention strategies that support disabled people to define their own health, well-being, and health care needs. Public health researchers are using disability theory to critically analyze how disabled people have been excluded from research studies. Public health practitioners also advocate for the elimination of health inequities between disabled and nondisabled people.[86] Some argue that a human rights framework is where public health and disability theory find synergy. From this perspective, disability

theory and public health together focus on health equity—ensuring all people have a right to their highest attainable health—and on the social drivers of health—eliminating oppressive barriers to health and well-being to support "social flourishing."[87]

Law

Disability legal studies and theory deconstruct how disability is defined and shaped in the law in order to preserve an ableist power structure. Disability legal scholar Sagit Mor explains: "The law in this view is an arena of struggle in which the meaning of disability is constantly formed and transformed, contested, negotiated, defied, and interrogated, constrained and liberated."[88] Hence, disability legal theorists and scholars dissect the "values, histories and intentions behind rules and court decisions"[89] in multiple areas of law, including welfare, civil rights, institutionalization, criminal justice, sterilization, euthanasia, and reproductive rights.

Disability legal theory is increasingly intersectional. Theorists point out how historically marginalized people have been devalued and subjugated based on normative categories that have elevated White, middle-class, cisgender, able-bodied men but also the ways in which their unequal treatment under the law was justified based on "the idea of medicalization and embodying social difference as biological."[90] For example, slaves were defined as mentally and physically different and inferior in order to justify their legally sanctioned oppression and bondage; immigrant, LGBTQ+, disabled, Black, and poor people were sterilized during the twentieth-century eugenics movement (which advanced the theory that human genetics must be tailored to increase superior traits in the U.S. population by excluding people and groups considered inferior and undesirable) with full support of the law; and, as noted earlier, women's bodies were considered anomalous and their health concerns labeled as mental and physical deficiencies and disabilities in order to justify their exclusion from public life.[91]

Conclusion

Historically, medicine, public health, and law have each played a role in sustaining definitions, norms, and practices that subordinate groups of people. Critical race, feminist, queer, and disability theorists continue to interrogate how the legacy of the subjugation of people deemed different and inferior continues to affect how these individuals and populations are treated today. Health justice demands that scholars, practitioners, and others continue to probe and disrupt the underlying assumptions in medicine, public health, law, and public policy that subordinate people based on their status. In Chapter 2, we turn to the role of social movements (often supported by critical theory) in not only driving law and public policy reform but also altering norms and attitudes. These movements have also helped transform medical and public health systems and practice and inspired medical, public health, and legal professionals to fight for social change.

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