

Preface

In 2021, our book *Evaluation in Today's World: Respecting Diversity, Improving Quality, and Promoting Usability* (Thomas & Campbell, 2021) was published after three years of writing during a very difficult time in our nation's history, including the worldwide COVID-19 pandemic and racial unrest following the George Floyd murder. Our goal in writing this award-winning text was to provide students, evaluators, and others with a deeper understanding of evaluation and the skills needed to analyze how power, privilege, and social injustices can influence various aspects of evaluation and how using those skills and that understanding would help evaluators improve the quality and usefulness of their evaluations. We were somewhat surprised and very pleased with the response the book received from the biomedical and public health communities, and were honored that it led, in large part, to our working with a variety of organizations, including the Centers for Disease Control (CDC), the Association of State and Territorial Health Officials (ASTHO), and the National Alliance of State and Territorial AIDS Directors (NASTAD). This work helped us better understand the uniqueness of health and health disparity programs and their evaluations, as well as the need for a book that addresses those unique challenges and opportunities for a framework that incorporates a racialized lens and a social justice perspective into culturally responsive evaluation (CRE).

Despite years of programs, policies, and legislative efforts, health disparities remain a major challenge in the United States. Exacerbated by the COVID-19 pandemic, health disparities, particularly in minoritized groups, continue to increase. There has been a backlash toward public health programs, particularly those dealing with marginalized groups due, at least in part, to disinformation, increased recognition of structural inequalities, and the limited success of many health programs. The need for evaluations that understand and acknowledge the role of structural inequalities in public health and yield robust, high-quality, and culturally responsive findings to guide decision-making is key to the continuation and improvement of efforts to improve public health.

Although health program evaluations employ the same scientific methods as other evaluations, they include additional factors that the evaluator must address, which set them apart from many other types of evaluations. These factors include, for example, attention to social determinants of health, particular ethical and equity considerations (such as reducing disparities, increasing access and utilization), and population characteristics (such as differences in baseline health status) that must be considered at every stage of the evaluation. Health program evaluators, in addition to possessing technical and statistical expertise, need to demonstrate respect and understanding of the cultural context in which they work and incorporate those understandings into their evaluations, foster collaborations with priority communities and other key audiences, reveal inequities when they arise rather than mask or ignore them, and challenge biased understandings of longstanding issues like victim blaming, stigma, and biased misconceptions about certain populations. The goal of this book is to equip students, practitioners, and others with the tools and knowledge to evaluate health programs through a culturally responsive, racialized and equity-focused lens, taking into account these and other considerations. Using this approach will yield results that better help health program planners and others understand what works and what doesn't in reducing health disparities, and why.

The primary audience for this book includes individuals teaching and taking graduate evaluation courses in health sciences and related fields, including public health, population health, clinical and translational sciences, and health psychology. It can also serve as a reference book, in whole or selected chapters, for those who, through professional development and other training, seek to enhance their skills in planning and conducting culturally responsive and equity-focused evaluations. Throughout this book, we strike a balance between theory, methods, and practice, providing readers with the necessary background to plan and conduct high-quality evaluations of health programs that promote the ideals of collaborative participation, social justice, and equity.

Adding to the uniqueness of the book is who we are. We see ourselves as a “perfect pairing” that brings added value to an evaluation textbook, combining years of academic and real-world experience. Pat Campbell, the first author, is a former associate professor of research, measurement, and statistics at Georgia State University and is now president of Campbell-Kibler Associates, Inc., a research and evaluation company. She is a full-time practicing evaluator and researcher. Veronica Thomas, the second author, is a professor of human development at Howard University and works part-time as a practicing evaluator.

In the early 1970s, I (Pat) worked with slain civil rights leader Medgar Evers’ brother Charles to register African American voters in Mississippi and served as an advisor on his campaign for governor of Mississippi. A decade later, I co-authored the *AERA Guidelines for Eliminating Race and Sex Bias in Educational Research and Evaluation* and later conducted educational evaluation and research training in South Africa and Uganda; I also served as an expert witness in the Citadel sex discrimination case. Along with working with Veronica on *Evaluation in Today’s World* and the current book, I spent a number of years, under NIH grants, exploring the challenges biomedical researchers, particularly those from marginalized groups, experience going through undergraduate, graduate, and post graduate education. Currently, I am also doing research on active learning and student engagement.

As the only African American elementary school student at an all-White elementary school in the South during the Civil Rights era, Veronica (second author) became deeply aware of issues related to discrimination, marginalization, and social injustices at individual, institutional, and societal levels from a very young age. As a professor teaching at Howard University, an HBCU (historically Black college and university), I found a home, consistent with my values, and a place, through my work, to be part of the “resistance” against racism, sexism, and other forms of marginalization. Since then, I (Veronica) have integrated social justice agendas into my teaching, research, and service work. The most fulfilling part of my professional career continues to be training and collaborating with African American and other students and young professionals of color who are dedicated to inclusive research and evaluation with (not on) marginalized and underserved communities. My programmatic and research passions center on the physical and psychological well-being of people of color, with a particular interest in promoting the health of African American women, families, and communities.

Contents Of The Book And Challenging Assumptions

This book focuses on the skills and knowledge needed to conduct high-quality health program evaluations. It covers many of the basics of what professors desire and are used to seeing in existing evaluation textbooks, such as a technical overview of different evaluation types (e.g., formative vs. summative), appropriate methods, designs, and types of data analysis that can be used in

health program evaluations, and coverage of non-technical issues such as theory, engaging priority audiences and ethical considerations. In addition, the text gives culture an explicit role while simultaneously attending to robustness and rigor within the program and community context. It provides readers with evaluation knowledge, tools, and practical strategies tied to health program development and evaluation through an equity-focused, culturally responsive, and racialized lens. The book addresses issues that cover a variety of topics not usually included in health program evaluation textbooks, such as how power dynamics, race, and racism can negatively impact evaluations and how evaluators can and should reduce that impact. Other topics we cover, that aren't usually included in health program evaluation textbooks, are:

- The use of race as an explanatory factor in health disparities;
- The deficit model and its problematic application in health program planning, implementation, and evaluation;
- Community distrust of public health efforts, and their impacts on health and health disparity programs and their evaluation;
- The ways cultural differences and inequities can impact data and data collection;
- The incorporation of social determinants of health in program planning and evaluation;
- The application of evaluation ethics with a specific focus on health settings in diverse cultural contexts and ethical issues surrounding historical trauma;
- The challenges of dealing with the politicalization of evaluation;
- The need for and ways to facilitate the responsive engagement of populations of focus and other strategies and benefits of engaging the “right” groups throughout the entire evaluation process; and
- The ways of reporting and disseminating evaluation results that are useful and used by diverse groups of interested people including people with disabilities.

This book challenges several old and ongoing assumptions that, if left unchecked, could potentially reinforce stereotypes and inequities, distort evaluation findings, and limit the impact of evaluation results. Evaluation has traditionally had as its goal to provide objective judgments of the quality and effectiveness of a variety of programs, policies, projects, and interventions. This focus on objectivity has persisted, even though for many years, researchers and philosophers of science have debunked the illusion of objectivity in science, research, and evaluation. As we rethink the role of objectivity in evaluation, we highlight the roles of subjectivity and bias. As evaluators, we bring our own values, perspectives, and cultural backgrounds to the evaluation context. To be good evaluators, we must acknowledge that we all have biases. We need to explore them, examine how they influence us and the work we do, and determine how we can work most effectively with and across our biases. This is not easy to write about or do. However, being explicit about values and biases builds credibility and increases the trustworthiness of evaluation findings. We include insights, examples, and lessons learned from our own work and the work of other evaluators wrestling with diversity and social justice issues in evaluation, in general, as well as specifically to the evaluation of health and health disparity programs.

Throughout this book, we directly confront issues of power and privilege as well as the assumptions that often accompany these dynamics. The reality is that evaluations are done, generally, at the request of those with power and resources. Government agencies, private

foundations, other funders, and program developers are those who either require evaluations or are required to have evaluations done. There is often an assumption that funders, program designers, and/or evaluators know best what should be the focus of a health program and its evaluation, and that their perspective is more valid than those of affected communities and people with lived experiences. In this book, we challenge that notion and argue for the inclusion of a diversity of perspectives throughout the entire evaluation process. Those who commission an evaluation influence the evaluation process, especially in terms of decisions about the questions that are asked, the variables over which data are collected to determine if a program or project is a “success,” and how, or even if, the results are used. The less powerful, often those with whom a program or project is designed to serve, frequently have little or no voice in shaping the evaluation questions asked or how success is defined. This can be a contributing factor as to why so many evaluations are not “on point” or as useful as they could and should be. The book offers practical tips and resources for addressing privilege and power dynamics in both health planning and evaluation.

A related, assumption we challenge throughout the book is the reliance on the dominant paradigm in planning and implementing health program evaluations. The dominant paradigm in evaluation, which has traditionally guided how evaluations are conducted, emphasizes neutrality and standardization. In contrast, the culturally responsive and equity-oriented approaches, we advocate throughout the book, emphasize diversity, context, inclusion, and social justice.

Organization And Pedagogical Features

Each chapter begins with a set of learning objectives or brief statements that describe what readers are expected to know and/or be able to do after reading the chapter and completing the activities. Examples and opportunities for discussion of perceptions and ideas are included throughout the chapters. Important terms are bolded at their first mention in the book and are defined in the glossary as well as in the first chapter in which they are used.

Four features—*Reflect and Discuss*, *Case Study*, *Activity*, and *Perspectives from Groundbreakers*—build on the book’s overarching theme and are designed to pique readers’ interest and extend their learning opportunities. *Reflect and Discuss* features an issue or question that readers critically think about and discuss in small groups. *Case Studies* present real or hypothetical cases that address the application of a particular theoretical, methodological, or practice issue in evaluation. *Activities* ask readers to do something (individually or in small groups, within class or outside class) involving the application of knowledge gained or issues raised in that particular chapter. *Perspectives from Groundbreakers* are commentaries from health equity and evaluation scholars, practitioners, and/or users about a particular issue of relevance tied to the chapter. The chapters each have a series of strategies and tips, based on the content of the chapter, that readers can use in their current and future evaluation work. Each chapter ends with an opportunity for readers to reflect on that what was covered in the chapter and an activity designed to allow them to apply what they have learned. This is followed by a description of supplemental resources for readers who wish to delve more deeply into the areas covered in the chapter. At the end of the book is a glossary of all bolded terms included throughout the chapters. Additionally, the references cited in the chapters are found following the glossary. In some cases, resources have been removed from governmental websites, and websites that are live now, in the future may no longer exist. In those cases, it is useful to search for the name of the resource in a search engine to see if it is available at another site.

Chapter 1

Using Evaluation as a Tool to Improve Health Programs and Reduce Health Disparities



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Despite considerable effort, health programs have not achieved their expected success, and, in many areas, health disparities have increased. Attending to considerations of diversity, culture, and equity can help program evaluators provide programs with the information they need to be more effective.

Learning Objectives

- 1.1 Describe the book's goal and major themes.
- 1.2 Describe what a racialized and social justice perspective with a social justice lens is and how it relates to culturally responsive evaluation.

- 1.3 Explain the impact that bias, stereotypes, and myths about objectivity can have on the quality and usefulness of health program evaluations.
- 1.4 List some of the challenges of doing health and health disparities program evaluation and strategies for dealing with them.
- 1.5 Describe similarities and differences between health program research and evaluation.

Introduction

Over the years, a wide variety of public health programs have been developed and implemented. However, in many areas, things are not improving, and in some areas, they are getting worse. The relative lack of success of previous efforts indicates the need for more and more effective evaluations. In a time when the very existence of such programs has been politicized, evaluations that produce high-quality data can and must be used to improve existing health programs, guide program decision-making, and provide direction for the development of new programs. The book is designed to provide evaluators with the tools and knowledge they need to evaluate health and health disparity programs and provide that **data**. The book's **goal** is to increase the quality and quantity of evaluations that can help determine what is and isn't effective in improving public health, reducing health disparities, and increasing our understanding of not just what works and doesn't, but why.

This chapter has two sections. The first section provides an overview of the book as a whole as well as of the individual chapters. It covers the pedagogical features of the book and introduces some of the book's major themes and concepts. The second section provides an introduction to evaluation, focusing on health and health disparity program evaluation, including ways bias, stereotypes, and myths about objectivity can negatively impact evaluations. It goes on to cover some of the major challenges facing evaluators of health and health disparity programs, as well as the similarities and differences between health and health disparity program evaluations and research.

The impact of public health and other health-related programs has been mixed. For example, while programs to reduce opioid overdose have been quite successful (CDC National Center for Health Statistics, 2025), rates of maternal mortality, women's mental illness, and multimorbidity have all been increasing (Clayton et al., 2025). Life expectancies in the United States continue to vary dramatically depending on where one lives, the economic conditions in that location, and one's racial and ethnic identity. These differences, which were large at the beginning of the 21st century, increased during the first two decades of the 21st century, and were dramatically exacerbated by the COVID-19 pandemic, leading to a "vital need to reduce the massive inequity in longevity in the USA" (Dwyer-Lindgre et al., 2024, para. 4).

Program evaluation and evaluators can and should play an important role in these and other efforts to improve public health. The book seeks to provide readers with the information and skills they need to conduct high-quality evaluations of health-related programs, including programs that focus on reducing the differences in health outcomes for people in different demographic groups.

Overview of the Book's Focus, Framework, and Structure

The Focus

The primary focus of the book is on evaluation and the knowledge and skills needed to implement evaluation, including planning, design, data collection, analysis, and report writing. The book acknowledges the reality that while evaluations of health programs depend on many of the same methods as other evaluations, there are a number of other factors that need to be addressed for health-program evaluations to be more comprehensive, accurate, and useful. One such factor is the existence of **health disparities**. Health disparities are “systematic, plausibly avoidable health differences affecting socially disadvantaged groups” (Braveman et al., 2011, para. 2). These groups can be defined by race/ethnicity, skin color, religion, or nationality; socioeconomic resources (reflected by such variables as income, wealth, education, or occupation); gender, sexual orientation, gender identity; age, geography, disability, illness, political or other affiliation; or other characteristics associated with discrimination or marginalization. These characteristics reflect social advantage or disadvantage as they contribute to the determination of an individual's or group's position in a social hierarchy (Braveman et al., 2011). **Health equity**, is described by the Centers for Disease Control (CDC, 2024b, para. 1) as “the state in which everyone has a fair and just opportunity to attain their highest level of health,” which is the opposite of health disparities. Improving the health of the public and moving toward health equity is a major goal of public health and an important component of health program evaluations.

Health program evaluations must be attentive to **social determinants of health (SDOH)**, non-medical factors that affect an individual's health. They are the “conditions in which people are born, grow, work, live, and age” as well as the “broader forces and systems that shape everyday life conditions” (CDC, 2024b, para. 2). As the CDC (2024b, para. 3) explained, “These forces and systems encompass economic policies, development agendas, social norms, social policies, racism, climate change, and political structures.” In addition, the lack of common health disparity indicators and metrics, including consistent definitions of success, can impact the quality of evaluations (Dye et al., 2019).

The Framework

As will be described in detail later in the chapter, the evaluation framework used in the book is an expansion of **culturally responsive evaluation (CRE)**, which is coupled with a racialized lens and a social justice perspective. CRE takes into account the cultural context in which an evaluation takes place and requires evaluators to critically examine culturally relevant, but often neglected, variables throughout the entire evaluation process. A **racialized perspective (lens) pays** attention to the ways in which race shapes problem definitions and solutions as well as different groups' access to opportunity. Race, or more accurately, race and ethnicity, “are a characterization of people based on having a shared culture ... related to common ancestry and shared history” (American Psychological Association Dictionary of Psychology, n.d., para. 1). A **social justice perspective (SJP)** brings up and attends to issues of equity, diversity, and inclusion throughout the evaluation process. It aims to uncover and make visible inequalities and injustices rather than masking them (Campbell & Thomas, 2021a).

As will be covered in the different chapters in the book, evaluations that have a racialized and social justice perspective with a CRE focus require attention to:

- What is focused on and what is missed in evaluations;
- Who is heard and who is silenced in evaluations;
- The evaluation designs used (and not used);
- The data collected (and data ignored);
- Who interprets, how interpretations are made, and whose interpretations are valued;
- What conclusions are drawn;
- How results are reported;
- To whom results are reported; and
- How results are used. (adapted from Campbell & Thomas, 2021a)

The Structure

Each chapter begins with a quote, which represents that chapter's themes. The quote is followed by a short introduction and a set of **learning objectives**, which are “clearly written, specific statements of observable learner behavior or action that can be measured upon completion of an educational activity” (Chatterjee & Corral, 2017, para. 1). Within each chapter, there are a variety of activities tied to the learning objectives, as well as case studies and examples related to health and health disparity program evaluations. Key evaluation and other important terms are bolded the first time they are included in a chapter and defined the first time they are used.

Each chapter includes an interview with health and health disparity program evaluators, researchers, and/or developers. The interviews, *Perspectives from Groundbreakers*, were conducted by the co-authors and focus on issues pertaining to that chapter. The chapters each conclude with a series of implementable strategies and tips, and an end-of-chapter reflection and application of issues covered in the chapter.

An annotated list of resources is included at the end of each chapter, which provides additional information on the areas covered. At the end of the book, there is a list of references, a glossary of the bolded terms, and an index. Online links to listed resources are included in the text. Links are also included in the references when they are available. This may mean, especially in times when government resources and websites are being erased, that in the future, some websites and resources will no longer be available. While this is very regrettable, we believe that the benefits of providing easier access to those who wish to use the resources or read the references are worth the risk of having some link and websites no longer be available. Similarly, some of the research studies and resources included in the text were available when we were writing the book, but have since been deleted by departments of the executive branch of the federal government. Because of the value of the information, we chose to continue to include them in the text, adding notes in the references when a reference was deleted.

The book, as a whole and individual chapters, covers how race and social justice issues impact different aspects of the evaluation of health and health disparity programs and how readers can increase their knowledge and build skills to improve the quality and usability of the evaluations they conduct. Within the book are five cross-cutting themes:

- Moving Beyond the Dominant Paradigm to Broaden Evaluation's Frameworks and Methods;
- Dealing With Bias;

- Engaging Populations of Focus Throughout the Evaluation Process;
- Using a Racialized Lens to Understand the Ways Race Shapes Programs and Their Evaluations; and
- Doing Evaluation in a Politicized World.

Throughout the book, the use of **artificial intelligence (AI)** in such evaluation related tasks as literature searches, generating evaluation questions, translation, transcription, coding qualitative data, and quantitative and qualitative analysis is covered. Discussed too are advantages of using AI as well as concerns about accuracy, equity, and ethical uses (Nielsen et al., 2024).

Language Used

Determining the most culturally appropriate terminology to use in this book and elsewhere is always a challenge. To meet the challenge, we have chosen to acknowledge the complexity and be transparent about the choices we have made. For example, reflecting the American Psychological Association (APA) and other style manuals, we use *they*, *them*, and *their* where the gender “is unknown, irrelevant, or nonbinary, or where gender needs to be concealed” (Baron, n.d., para. 1). Using *they*, *them*, and *their* in this way is not new. The first reported usages of *they*, *them*, and *their* as singular pronouns were found, by the Oxford English Dictionary, to be over 700 years ago in 1375 (Baron, n.d.).

We tend to use African American when we refer to people whose origins are in the African continent but whose history is on the American continent, and Black when we are speaking more generally. However, we use the terms African American and Black fairly interchangeably when quoting others to describe a person’s race/ethnicity. We chose to use Hispanic as a generic collective term because it encompasses people from outside as well as inside Latin America. We use Asian American as the common designation for people in the United States of Asian descent, and Indigenous Person to identify members of the 562 different tribes in the United States. These terms don’t acknowledge the great diversity within each of the groups, and we use the more specific terms when referring to subgroups. We also use person-first language, using, for example, a person with a disability rather than a disabled person and a person who smokes rather than a smoker. This usage puts the focus on the individual, rather than equating them with their condition or situation.

The meaning, usage, and acceptability of terms change over time. For example, the word queer “entered the English language by the early 16th century, when it was primarily used to mean strange, odd, peculiar, or eccentric. By the late 19th century, it was being used colloquially to refer to same-sex attracted men. While this usage was frequently derogatory, queer was simultaneously used in neutral and affirming ways” (Jones, 2023, para. 3). By the 1990s, the term *queer theory* came into being, with *queer being* used to define a gender or sexual identity that was non-conforming (Jones, 2023).

The appropriateness of the use of terms changes over time as well. For example, the term *stakeholder* has been used by evaluators for many years. However, as discussed later in Chapter 6, as awareness of negative connotations that the term can have in terms of colonialism and power grows, its use has become problematic and terms such as *populations of focus*, *community members*, *partners*, *collaborators*, and *allies* are more appropriate (MacDonald & McLees, 2021). Other than when the term *stakeholder* is used in direct quotes, we do not use it in the book.

Chapter Content

The book is composed of 12 chapters. This, the first chapter, as described earlier, provides an overview of the book and its underlying premises, including some of the major challenges facing evaluators of health and health disparity programs. The second chapter focuses on health disparities, both past and present, and how race and racial bias intersect with other demographic variables to contribute to those disparities. Also covered in this chapter are the possible impacts of the inaccurate views of race as a biological/genetic construct on programs and their evaluations, the use of the deficit model in both health programs and their evaluations and the use of AI in the generation of health algorithms.

Chapter 3 examines theories commonly used in health-program planning, implementation, and evaluation. It considers the interconnectedness of theories of health behavior, health interventions, and program evaluation, and also discusses how and why evaluation theories play a major role in guiding evaluation practice. Particular attention is given to challenges and opportunities of applying theories when focusing on populations that have been historically marginalized and underrepresented in health research and evaluations. Chapter 4 focuses on health-program and evaluation planning from a culturally responsive and equity perspective. It highlights the importance of integrating program planning and evaluation planning. It also includes some tools (e.g., logic models and Gantt charts) that both health-program planners and evaluators can use to guide the planning process. Chapter 5 discusses the intersection between ethics, social justice, culture, and evaluation. The *Ethical Guiding Principles for Evaluators* and *Program Evaluation Standards* are examined, along with social justice evaluation approaches that prioritize ethical and social justice stances. Chapter 6 discusses the importance of engaging with priority populations, communities, program partners, and relevant institutions throughout the entire evaluation process. It includes a brief overview of the historical foundation for engagement with priority audiences. Strategies for rebalancing power dynamics and engaging with communities in culturally appropriate, respectful, and meaningful ways are provided. Chapter 7 focuses on the importance of asking evaluative questions to better understand health disparities and advance equity. There is emphasis on asking questions that matter, questions that address issues key audiences care about, and questions that consider equity considerations. It also covers the characteristics of good evaluation questions and examples of different types of evaluation questions.

Chapter 8 focuses on collecting data so all relevant voices are heard. It includes a discussion of the knowledge and skills needed to make decisions about the best ways to access needed data and how to select and/or develop the most appropriate measures and data collection techniques. **Validity** and **reliability** in relation to different data collection methods are discussed as well as the protection of human participants.

Chapter 9 covers the overlap between evaluation and research designs and provides an overview of the most commonly used evaluation designs and their strengths and weaknesses. Also covered are the advantages of and ethical concerns of using comparison groups. The role of **rigor** is examined, and the concept of **robustness** is introduced. Chapter 10 focuses on data analysis and introduces inductive and deductive analytic frameworks. Also discussed are the strengths and weaknesses of different **qualitative** and **quantitative** data analyses. Cultural and analytic issues tied to **intersectionality** and **data disaggregation** and **aggregation** are included.

Chapter 11 focuses on reporting and disseminating findings from evaluations of health programs and making findings engaging, useful, and used. It covers different types of evaluation reports used to disseminate evaluation findings to different groups and ways to communicate evaluation results in culturally responsive ways. Chapter 12, the final chapter, reexamines the

book's themes and provides opportunities for readers to synthesize the information covered in the book and refine some of the skills they have learned, as well as ways to conduct evaluations in an increasingly polarized country.

An Overview of Evaluation and Related Concepts

Defining Evaluation

People make evaluative decisions multiple times daily. Some decisions are small, like “Should I have butter pecan or chocolate ice cream?” Some are larger, such as “Should I go to the doctor or treat my ear infection on my own?” Others can be life-changing like “Should I go to graduate school for a Master’s of Public Health (MPH) degree?” In these everyday **evaluation decisions**, we assess options to determine which will provide the best outcomes. As the following definitions of evaluation indicate, common understandings of **summative evaluation** focus on making judgments based on something’s value and/or worth.

- Evaluation is the determination of the value, nature, character, or quality of something or someone (Merriam Webster, n.d.-c);
- Evaluation is a systematic determination and assessment of a subject’s merit, worth, and significance, using criteria governed by a set of standards. (Wikipedia, n.d.); and
- Evaluation is the process of judging or calculating the quality, importance, amount, or value of something (Cambridge Dictionary, n.d.-a).

While definitions of professional evaluation vary, they are built upon these more general definitions. Over 30 years ago, Scriven (1991, p. 139) described evaluation as “the systematic definition of the merit, worth, and significance of a program, project, or policy endures.” Expanding on his definition, Davidson (2014, p. 1) explained that “evaluation, by definition, answers evaluative questions, that is, questions about quality and value. This is what makes evaluation so much more useful and relevant than the mere measurement of indicators or summaries of observations and stories.”

Definitions of program evaluation that focus on health and health programs overlap with more general definitions of program evaluation. For example, the *Free Dictionary by Farlex: Dictionary* (n.d., para. 1) defines program evaluation of health programs as: “a critical appraisal or assessment; a judgment of the value, worth, character, or effectiveness of something” while the *Farlex Partner Medical Dictionary* (n.d.) defines it as “systemic, objective assessment of the relevance, effectiveness and impact of activities in the light of specified objectives” (para. 1).

The Centers for Disease Control (CDC), in their 2024 *Program Evaluation Framework*, described “evaluation as a critical function that communities and organizations should undertake to improve and strengthen their activities and systems” (Kidder et al., 2024, p. 1). As they explained, “program evaluation uses systematic data collection and analysis of programs, policies, and organizations to assess their effectiveness and efficiency” (p. 1). Their *Framework* lists a variety of ways health program evaluations can impact programs, including determining program strengths, weaknesses, and areas for improvement throughout a program’s life cycle. Health-program evaluations can assess the adequacy of program resources, accuracy of program assumptions, quality or fidelity of program operations, and the intended and unintended effects of a program. Importantly, evaluations can help clarify “why a program is or is not being

implemented as planned or producing intended results, and why certain trends or patterns are observed in existing data sources” (Kidder et al., 2024, p. 1).

After reviewing a variety of definitions of program evaluation, we developed our own comprehensive definition of evaluation. We define it as “a disciplined inquiry involving the systematic, contextually responsive, and ethical application of research tools and methods to collect data that assess the effectiveness and operations of programs within the various social, political and cultural contexts in which they operate” (Thomas & Campbell, 2021a, p. 6). Evaluation’s ultimate goal is to provide credible evidence that fosters greater understanding and improves decision-making, all aimed at improving social conditions and promoting healthy, just, and equitable communities” (Thomas & Campbell, 2021a, p. 6). Our definition emphasizes the contexts in which individuals involved in the program, such as participants, staff, funders, and others, as well as the program itself, operate.

In the following activity, readers are provided with an opportunity to develop their own definition of program evaluation

Activity: How Do You Define Program Evaluation?

Write down some of the components that you think should be included in a definition of program evaluation, and then decide if there are any changes you would make to apply that definition to the evaluation of health and health disparities programs. In small groups, share your answers and look for possible commonalities in your responses.

The Centers for Disease Control (CDC) 2024 Evaluation Framework

Different definitions of evaluation, including those of the CDC’s, the authors, and possibly yours, are well represented in the CDC’s Framework in Figure 1.1.

The outer circle of the framework includes three cross-cutting actions that are foundational to high quality evaluations and to this book. These are to advance equity, engage collaboratively, and learn from and use insights. The following textbox provides CDC’s descriptions for each of these terms.

Advance Equity: Health equity is defined as the state in which everyone has a fair and just opportunity to obtain their highest levels of health. Evaluators can help advance equity and eliminate health inequities in many ways:

- By using collaborative and equitable evaluation approaches to create environments where everyone is respected and heard;
- By considering the effects of potential decisions and their impact on the advancement of equity throughout each step of the framework, and when applying the standards;
- By proceeding with cultural responsiveness and recognition of shared experiences to integrate the uniqueness of each context into the design and implementation of an evaluation; and
- By conducting evaluations that uncover factors perpetuating health inequities.

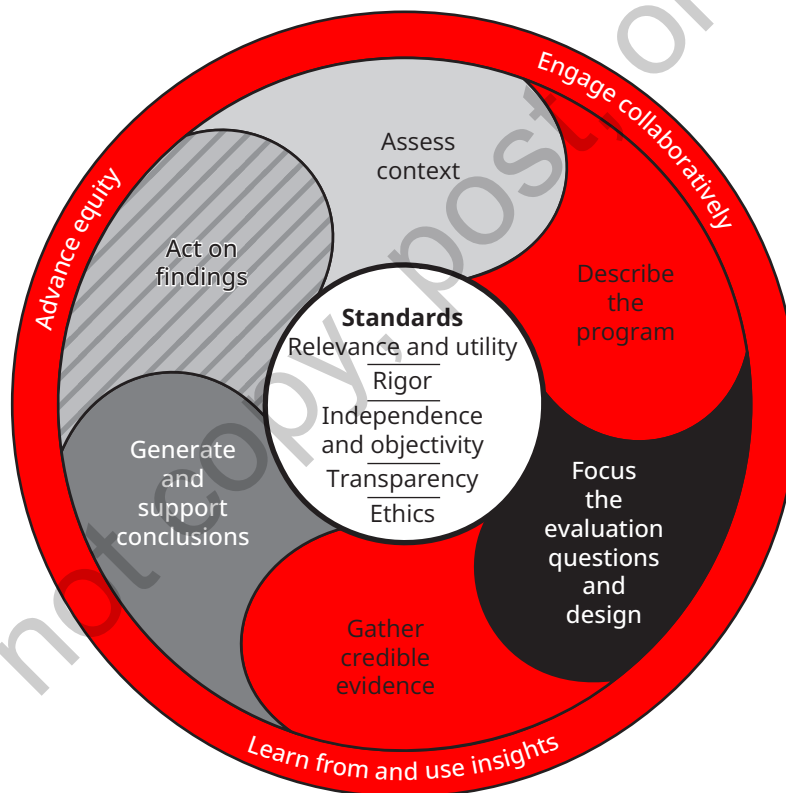
Engage Collaboratively: Evaluators can facilitate co-ownership of the program evaluation with interest holders. By doing so, the evaluator can increase the validity of the

evaluation findings and improve the likelihood that results are used by interest holders. This collaboration starts at the beginning of the evaluation planning process and continues into the implementation and interpretation phases.

Learn From and Use Insights: Evaluators also serve as facilitators for continuous learning, use of findings, and improvement through evaluation. Successful evaluators build relationships, cultivate trust, and model the way for interest holders to see value and utility in evaluation insights. (Kidder et al., 2024, p. 1)

The CDC framework also describes six steps in the evaluation process, covering evaluation planning, implementation, and reporting and use of results. As depicted in the graphic in Figure 1.1, these steps include: (1) assess the context, (2) describe the program, (3) focus the evaluation questions and design, (4) gather credible evidence, (5) generate and support conclusions, and (6) act on findings. The process is iterative. While the earlier steps provide the foundation for subsequent progress, contextual constraints or nuances are often revealed in the later steps (e.g., Steps 4 and 5) and may require modifying the decisions made in the earlier steps.

Figure 1.1 ■ CDC Program Evaluation Framework (2024)



Kidder, D. P., Fierro, L. A., Luna, E., Salvaggio, H., McWhorter, A., Bowen, S-A., Murphy-Hoefer, R., Thigpen, S., Alexander, D., Armstead, T. L., August, E., Bruce, D., Clarke, S. N., Davis, C., Downes, A., Gill, S., House, L. D., Kerzner, M., Kun, K. ... CDC Evaluation Framework Work Group. (2024). CDC Program Evaluation Framework, 2024. *MMWR Recommendations and Reports*, 73(RR-6), 1–37. <https://www.cdc.gov/mmwr/volumes/73/rr/pdfs/rr7306a1-H.pdf>

Phases and Activities Across the Evaluation Process

Regardless of the specific details of individual definitions of evaluation, evaluators seek to provide information that improves decision-making at various levels—funders, policymakers, staff, and actual and potential participants. The evaluation process has three major phases—planning, implementation, and reporting/use of results. Figure 1.2 describes specific activities involved in each of the phases.

Figure 1.2 ■ Phases of the Evaluation Process

Planning→	Implementation→	Reporting/Use of Results
<ul style="list-style-type: none"> • Analyze project culture and context • Clarify objectives • Identify questions and indicators • Select measures and an evaluation design • Develop management procedures, including a budget 	<ul style="list-style-type: none"> • Pretest or pilot testing as necessary • Gather credible evidence (data collection) • Conduct data analysis, interpretation, and synthesis 	<ul style="list-style-type: none"> • Report findings • Disseminate findings and share lessons learned • Encourage use of results • Determine next steps, if any
↑	↑	↑
Involve and Engage Diverse Audiences		

Internal and External Evaluation and Evaluators

When considering evaluation, the question arises as to whether the evaluation, and the evaluator, should be internal or external. An **internal evaluation** is one where the evaluator is a staff member or someone within the organization of the program being evaluated. In an **external evaluation**, the evaluation is done by someone or a team who is independent from the organization or program being evaluated. External evaluators, often contracted from universities, consulting firms, and research institutes, generally possess broader and more specialized evaluation expertise than internal evaluators and bring a different perspective to the evaluation because they are not affiliated with the project (W.W. Kellogg Foundation, 2017). Various issues are taken into consideration in a program's decision to do an internal or external evaluator, including, for example: (a) the complexity of the evaluation, (b) costs/resources, (c) requirements of the funder, (d) perceived objectivity, and (e) specialist skills and expertise (Thomas & Campbell, 2021a).

A major advantage of an internal evaluator is that this person is generally familiar with the project's organization, the project itself, and its staff. Internal evaluators have access to organizational resources and likely already have a rapport with project staff, which provides more opportunities for informal feedback. They may be less threatening to project staff and better positioned to ensure that evaluation findings are used. This information can be useful when generating and prioritizing contextually relevant evaluation questions. However, in many cases, internal evaluators, who may be more cost-effective, lack the outsider perspective and technical skills of external evaluators (W. W. Kellogg Foundation, 2017). External evaluators, who bring

specialized skills and expertise, are generally viewed as more objective and have greater credibility with funders and other external bodies.

The **hybrid (or mixed) model**, which combines an internal evaluator with the external evaluator, coupled with any additional evaluation team members assembled by the evaluators, is often a stronger model. Having an internal and external evaluator co-develop evaluation questions, with input from key audiences, can provide a balance of relevance and rigor. Additionally, the hybrid model, which involves an internal and external evaluator working together, helps develop internal staff evaluation skills and can increase the program's ownership of recommendations while utilizing the expertise and "objectivity" of an external evaluator (Conley-Tyler, 2005; Thomas & Campbell, 2021a).

Program Evaluation and Research on Programs

There are a number of similarities between program evaluations and research on programs. Both draw on similar bodies of knowledge and frequently use the same designs, measures, data collection methods, and analyses. Because of this, there can be confusion as to what is research and what is evaluation. While there are a number of similarities, there are major differences as well. One major difference is in their purpose. The primary purpose of research is to produce new knowledge and to contribute to generalizable knowledge. As indicated earlier, the primary purpose of evaluation is to collect, analyze, and share data to be used in decision making and to provide findings and recommendations that can be used to improve ongoing programs and participating organizations (Kidder et al., 2024). Table 1.1 provides an overview of the differences between research and evaluation in six different domain areas.

Table 1.1 ■ Program Evaluation vs Program Research

Domain	Research	Evaluation
Questions	Grows out of previous research, theory, or evaluations	Grounded in the everyday realities of organizations and programs
Purpose	Moves the knowledge base forward	Assesses the quality/effectiveness of a product, process, or project
Context	Traditionally non-politicized; political and organizational contexts are less dominant	Political and organizational contexts are dominant
Focus	A population	A program
Generalizability	Results generalizable to individuals with the same characteristics as the study population/sample	Results not generalizable outside the current program
Findings	Contribute to the scientific knowledge base	Assess program quality/improve program design
Outcomes	Contribute to a broader theoretical understanding and are typically published to reach a wide audience	Provide actionable insights designed to influence immediate practice or policy

(adapted from Campbell & Hill, 2013, p. 2; EvalCommunity, n.d.-e, paras. 3-6)

In the following activity, readers decide if they would consider this article to be an evaluation of a program or research on a program.

Activity: Is It Research or Evaluation?

Read the following abstract and decide if you would describe it as program evaluation or research and why you made the choice that you did.

Purpose: To compare the effectiveness of adding a digital childhood obesity prevention intervention to health behavior counseling delivered by pediatric primary care clinicians.

Design, Setting, and Participants: Individually randomized, parallel-group trial conducted at six U.S. medical centers and enrolling patients shortly after birth.

Interventions: In the clinic-based health behavior counseling (clinic-only) group, pediatric clinicians used health literacy-informed booklets at well-child visits to promote healthy behaviors (n = 451). In the clinic + digital intervention group, families also received health literacy-informed, individually tailored, responsive text messages to support health behavior goals and a web-based dashboard (n = 449).

Primary Outcome: Child weight-for-length trajectory over 24 months. Secondary outcomes included weight-for-length z score, body mass index (BMI) z score, and the percentage of children with overweight or obesity.

In small groups, discuss your choice and your reasoning.

(adapted from Heerman et al., 2024)

This was an activity with no clear right answer. There are reasonable justifications for referring to it as evaluation or research. And, as is discussed in Chapter 7, in some cases, a project may include both research and evaluation questions and thus be classified as both. In many ways, it is necessary to determine how the information will be used to make a definitive choice.

Evaluative Thinking

At the core of evaluation is the concept of evaluative thinking. While evaluative thinking is a key component of evaluation capacity and practice (Baker & Bruner, 2012; Patton, 2021), definitions of evaluative thinking vary and are often abstract, describing it as analytic thinking or reflective practice. However, some definitions of evaluative thinking provide practical guidance to evaluators. For example, Buckley et al. (2015, p. 378) defined evaluative thinking as “critical thinking applied in the context of evaluation, motivated by an attitude of inquisitiveness and a belief in the value of evidence, that involves identifying assumptions, posing thoughtful questions, pursuing deeper understanding through reflection and perspective taking, and informing decisions in preparation for action.” The New Zealand Ministry of Education’s definition (Evaluation Hub, 2025, paras. 2-3) provides even more detail. It describes evaluative thinking as “a way to approach a course of action—a programme, briefing or even just a meeting—in a way that focuses on achieving the outcomes. Evaluative thinking involves constantly reflecting and questioning to make informed decisions. It is the state of mind that accompanies continuous improvement.”

Using evaluative thinking, evaluators:

- Collect information before making up one’s mind;
- Seek various points of view before coming to a conclusion;
- Think extensively about a problem before responding;

- Calibrate the degree of strength of one's opinion to the degrees of evidence available;
- Think about future consequences before taking action;
- Explicitly weigh pluses and minuses of situations before making a decision; and
- Seek nuance and avoid absolutism (Stanovich, 2010, p. 36).

Evaluative thinking can start by simply asking and answering questions and investing in the process of answering them. In the following activity, readers can ask and answer questions to develop evaluative thinking.

Activity: Applying Evaluative Thinking

The following are three topics and related questions that readers can ask themselves during an evaluative thinking process:

- **Identify and Challenge Assumptions & Assertions**
 - "What are we assuming? Do we actually know that?"
 - "How do we know that?"
 - "What makes you say that?"
- **Seek Out Blind Spots**
 - "What are we missing?"
 - "Whose perspective isn't represented?"
 - "What other explanations could there be?"
- **Capture Musings & Learning Questions**
 - "I wonder if ..."
 - "I bet if we ..."
 - "If I knew _____, I could _____."

Read the following text.

Culture

While there are almost as many definitions of culture the Center for Advanced Research on Language Acquisition (CARLA) define *culture* "as the shared patterns of behaviors and interactions, cognitive constructs, and affective understanding that are learned through a process of socialization. These shared patterns identify the members of a culture group while also distinguishing those of another group." While we often think of culture groups in terms of ethnicity or nationality, they can be any group with shared patterns of behavior and understandings such as evaluators, scientists, or even Boston Red Sox fans. Most of us are part of many different culture groups.

Evaluators need to be aware of the major culture groups which may have relevance for the evaluation ... An evaluation team needs to include people who are familiar with the major culture groups that have relevance for an evaluation. These may be people who are members of those groups or people who have experience working with those groups. Knowing such basics as appropriate levels of formality in language and dress, how people are addressed, and what behaviors are considered rude can make a big difference on the evaluation—especially the data collection. (adapted from Campbell & Jolly, n.d.-b para. 1)

After reading the text, select several of the evaluative thinking questions and answer them about the text you have just read. In small groups, discuss your answers

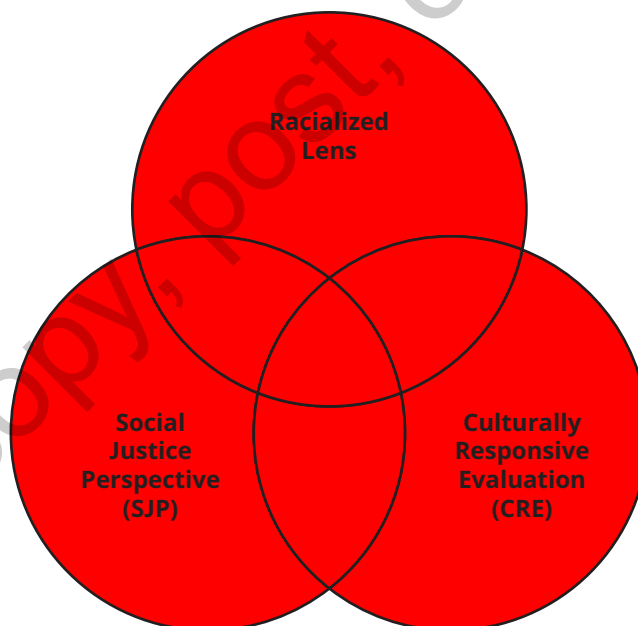
(IllumiLab, 2018, para. 6)

(adapted from Thomas & Campbell, 2021a, pp. 8-9).

Evaluation Based on a Culturally Responsive, Racialized, and Social Justice Framework

We can better ensure high-quality evaluations that are accurate, ethical, useful, and used through the application of a racialized lens coupled with culturally responsive and social justice-oriented frameworks, methods, and practices that address inequities and structural factors impacting the lived realities and outcomes of marginalized people (Campbell & Thomas, 2021a). As Figure 1.3 indicates, the components intersect.

Figure 1.3 ■ The Big Picture



Culturally responsive evaluation (CRE) takes into account the variety of contexts, including cultural, political, and environmental, in which the program and the evaluation take place. CRE requires evaluators to critically examine relevant but often neglected variables such as historical trauma, stigma, and resulting distrust of medical and evaluation professionals across the entire evaluation process. In CRE, every aspect and stage of evaluation needs to take into account and be responsive to the situations and environments impacting participants. CRE is a well-accepted and respected evaluation framework and a necessary, but not sufficient, aspect of

program development and evaluation, especially for programs that focus on eliminating health disparities and creating opportunities for people to live healthy lives. Attention to racialized and social justice issues is needed to provide a lens with which to examine why efforts to eliminate racial health disparities have not been more successful and to determine the programs and tools necessary to develop and assess high-quality, culturally responsive health programs and other efforts.

In the United States, “women, members of the LGBTQ community, people with disabilities, and members of religious communities, such as people of the Jewish and Muslim faith, have been the victims of institutional disparate and unfair treatment” (National Association of Social Workers, n.d., para. 3). “However, it undisputed that from a racial/ethnic standpoint, Black, Latinx, and Native American people have felt the brunt of systemic inequality over centuries” (National Association of Social Workers, n.d., para. 3). This is a major reason why the evaluation perspective taken in this book includes a **racialized lens or perspective**. Under a racialized lens, attention is paid to the ways in which race and ethnicity shape problem definition and solutions as well as particular groups’ access to opportunity. The existence of differential treatment, unequal access, and discrimination must be factored into effective program development and evaluation.

Using a racialized lens facilitates evaluators’ ability to critically examine situations where their own racialized and cultural beliefs, expectations, experiences, ideas, and biases could impact the work they do as well as to better understand the experience of those for whom racism and/or oppression is a constant and continuing reality. It allows movement beyond a White **dominant culture** to include the perspectives of other groups and a greater understanding of the barriers and challenges others face (Quinn & Grumbach, 2015). As covered in Chapter 2, this can help evaluators and others not to accept a **deficit model**, where the populations of focus and/or their individual members of those populations are defined in terms of their “perceived deficiencies, dysfunctions, problems, needs, and limitations” (Dinishak, 2016, para. 2).

Building on the work of Dolan-Reilly (2013), the National Association of Social Workers (n.d., para. 2) defines **social justice** as “the belief that everyone deserves equal rights, opportunities, and treatment regardless of their race, economic status, sexuality, or gender identity ... [It] must be considered in the context of historical systemic inequities in America’s social, economic, and political systems, and the long-term generational consequences of systemic injustice.” Social justice is closely tied to efforts to reduce health disparities. Health disparities are “of particular relevance to social justice because they may arise from intentional or unintentional discrimination or marginalization and in any case are likely to reinforce social disadvantage and vulnerability ... Health equity is social justice in health” (Braveman et al., 2011, para. 8).

In evaluation, a **social justice perspective** (SJP) uncovers and makes visible disparities, inequalities, and injustices while also attending to issues of equity, diversity, and inclusion throughout the evaluation process. This perspective helps evaluators notice things that might otherwise go unnoticed (e.g., heightening their sensitivities toward injustices), and it calls for evaluators to document inequitable benefits and burdens of the project across different racial/ethnic and other groups that are marginalized. It is particularly important for health and health disparity programs since they work with and serve diverse populations, many of whom have been treated unequally and marginalized. As such, it is key to examine social justice issues when evaluating these types of programs.

The following questions can help evaluators put these concepts into practice.

- Are there disparities in access, quality, and uptake of the intervention? If so, are there policies or practices that inadvertently (or advertently) promote these disparities?

- What strategies are being undertaken to repair significant historical mistrust of the health care, social services, and the criminal justice system that communities of color have?
- Is attention paid to community and individual issues and contexts in the program and in the evaluation of data collected, analyzed, and reported?
- Have policies and practices changed as needed to move the program toward a more social justice perspective?
- Are group differences being reduced while all gain? Or do all gain, but group differences remain the same or even increase? (Thomas & Campbell, 2024).

Rethinking Health and Health Disparity Program Evaluation

The evaluation of health-related services and programs, including health disparity programs, is, or needs to be, an important component of these programs. High-quality evaluations of funded programs should be required, and the facilitation of program evaluation should be a significant component of program directors' responsibilities. "The use of evaluation techniques in health disparities research is key to identifying the "active ingredients" that make health disparity interventions effective. Evaluation can play a dual role by providing evidence on the outcomes of the intervention within different settings and by appraising the intervention process to help clarify how and why the intervention worked and its cost ... facilitate progress toward reducing health disparities and improving health and well-being for all" (Dye et al., 2019, p. 15).

Yet, as Dye et al. (2019, p. 1) point out, "Despite the importance of evaluating health disparities research to produce high-quality data that can guide decision-making, it is not yet a customary practice." Often, when evaluation is done, it is done by the program's director and/or staff or by staff from other programs [internal evaluators]. While they will have the knowledge of health issues and health programs, which is an important component of health program evaluation, it's not enough. Many health professionals do not view program evaluation as its own discipline (Davidson, 2005). Without training in evaluation, health professionals lack the requisite knowledge, attributes, and skills to adequately evaluate the what and whys of program impact, or lack of program impact (Adams & Neville, 2020; Frye & Hemmer, 2012). This can lead to evaluations of health programs that "show no evidence of the application of any evaluation-specific methodology, and accordingly no robust and clear determination of the program's quality or value is made" (Adams & Neville, 2020, para. 7).

In his 2025 Perspectives from Groundbreakers interview, Alex Orgeta spoke of the skills evaluators of health and health disparity programs need to have.

Perspectives from Groundbreakers

Alex Ortega: Reflections on the Skills Health Program Evaluators Need to Have

Evaluators of health and health-disparity programs need to have good analytical skills. That's number one. Much of this work is not done in isolation and it's not done individually; it's done in teams. Students have to learn how to work in teams. That includes not just working with academics, but with community partners and community members as well as representatives

from other sectors like the health care system, government, and public health. They need the ability to communicate well to communities.

Things are interrelated, and they don't just happen in isolation. It's important for students to have that perspective. Students think of single isolated issues, like insurance coverage or access to care or healthy eating or access to healthy foods or whatever, pick the topic. These inequities don't happen in isolation. They're impacted by multiple factors. I think it's important for evaluators looking at health-disparity programs to understand the history of these inequities, where they came from, and how they were exacerbated.

Alex Ortega, PhD, is the dean of the Thompson School of Social Work & Public Health at the University of Hawaii. His research focuses on social justice and health disparities. Patricia B. Campbell interviewed him in winter 2025.

In addition, a good health program evaluator/evaluation team should:

- Have experience in the type of evaluation needed;
- Have the ability to grasp the project quickly after an understanding of its context and relevant communities;
- Demonstrate a willingness to work collaboratively with a wide variety of diverse audiences to meet project needs;
- Have an understanding of research designs and statistical methods;
- Demonstrate a willingness and skill set to address cultural/contextual factors in the evaluation;
- Work collaboratively with program staff to incorporate evaluation into program activities and provide ongoing feedback for program improvement;
- Offer innovative approaches to evaluation while considering the realities affecting a program (e.g., political constraints);
- Select, adapt, and create appropriate measures;
- Behave ethically and treat data confidentially;
- Have a willingness to educate program personnel in the importance of evaluation;
- Provide intended audiences with the full range of findings (i.e., not exaggerating positive results, or glossing over or failing to report specific negative findings);
- Communicate in simple, practical terms;
- Understand both the potential benefits and risks of evaluation in context; and
- Have the time to do the evaluation (adapted from Thomas & Campbell, 2021a).

Challenges to Doing High-Quality Health and Health-Disparity Evaluations

As indicated earlier and covered in detail in Chapter 2, while there have been a wide variety of health and health-disparity programs, improvement in general health and reduction of health disparities has been mixed, particularly in areas such as maternal and infant morbidity and mortality (Kornstein, 2021; National Academies of Sciences, Engineering, and Medicine, 2021). Evaluations that do not consider the impact of societal factors and do not pay attention to the potential impact of structured racism on the programs being evaluated, are less helpful in determining why programs are less successful than expected (Campbell et al., 2022). More useful evaluations apply a racialized lens coupled with culturally responsive and social justice-oriented frameworks, methods, and practices that address inequities and structural factors. The following are some of the challenges and considerations of doing these types of evaluations.

Objectivity and Rigor

Traditionally, objectivity and rigor have been the standard for judging research and, increasingly, for evaluations. However, objectivity in evaluation is a myth. As Kalanithi (2016) explained that “Science is based on reproducibility and manufactured objectivity. As strong as that makes its ability to generate claims about matter and energy, it also makes scientific knowledge inapplicable to the existential, visceral nature of human life, which is unique and subjective and unpredictable” (para. 2). Evaluation is about humans and human life. It is a social practice of valuing, whereas some evaluations (and evaluators) advance some values and not others. The perspective that determines which values are advanced and which are not is at least partially shaped by variables such as race, gender, and class (Martin et al., 2014).

Objectivity has been a component of definitions of rigor. However, as covered in Chapter 9, definitions of rigor are neither static nor objective. They are socially constituted, reflective of mainstream presumptions and social hierarchies, and can differ by discipline (Riley, 2017). “What is and isn’t considered “rigorous” is often decided by those who have power and influence. An overemphasis on rigor can cause some voices not to be heard equally, or at all, and can allow important differences in cultural context to be left out, making an evaluation less strong” (Thomas & Campbell, 2021a, p. 149). Bias can contribute to this.

Bias

As the following definitions indicate, there are a variety of definitions of **bias**:

- A preference or an inclination, especially one that inhibits impartial judgment (American Heritage Dictionary, n.d., number 2);
- The action of supporting or opposing a particular person or thing in an unfair way, because of allowing personal opinions to influence your judgment (Cambridge Dictionary, n.d.-b, para. 1);
- An inclination of temperament or outlook especially: a personal and sometimes unreasoned judgment (Merriam-Webster, n.d.-b, para. 1); and
- A tendency or preference towards a certain group, idea, or concept that influences our judgments and decisions (Gould, 2023, para. 1).

As these and other definitions of bias point out, biases impact one's judgment. "Bias can play a significant role in day-to-day interactions and relationships, often influencing our thoughts, attitudes, and behaviors toward others. This can result in misinterpreting or overlooking facts and can change how we perceive people or events in our lives." (Yasish, quoted in Gould, 2023, para. 3).

Biases can be explicit or implicit. As the name implies, **explicit biases** are those "preferences, beliefs, and attitudes of which people are generally consciously aware, endorsed, and can be identified and communicated" (Vela et al., 2022, p. 1). **Implicit biases** are "unconscious mental processes that lead to associations and reactions that are automatic and without intention and actors have no awareness of the associations with a stimulus" (Vela et al., 2022, p. 14). Even though people are unaware that their implicit biases exist, they, as well as their (and others) explicit biases, have a significant impact on decision making.

We all have biases, both explicit and implicit. Some are benign such as New Englanders' bias against the New York Yankees. Others, like biases against people because of their religion or race, are not. While explicit biases had been declining in the United States, recently they have been on the rise, and implicit bias continues to be unrelenting. People, including those involved in the health professions, hold negative implicit and for some explicit "biases against many marginalized groups of people, including racial and ethnic minoritized populations, disabled populations, and gender and sexual minorities, among others" (Vela et al., 2022, para. 1).

Cognitive biases are quite different from explicit and implicit biases. They "are patterns of thinking that distort or skew information processing, often leading to errors. These biases often occur when we make a quick decision using intuition or heuristics, which are simple rules or shortcuts that we use to make decisions and solve problems quickly without necessarily considering all available information (Clearer Thinking Team, 2023, para. 1; Tversky & Kahneman, 1970). They can lead to the misinterpretation of results and questions about the quality and efficiency of a process, product, or outcome (Dye et al., 2019). Several other biases have particular relevance for evaluators. These include:

Attribution bias is where we view the behavior of others as impacted by internal motivation—such as morals and character—while considering our own behaviors as affected by external factors, such as circumstances and environment (Gould, 2023). This bias is tied to the deficit model.

Confirmation bias occurs when we seek out and/or interpret information in a way that confirms and/or reinforces our existing beliefs. This bias can be problematic in generating conclusions and recommendations based on the collected data and in assessing the frameworks and logic models underlying the programs being evaluated (Gould, 2023).

Conformity bias is when we simply agree—or conform—with the opinions and behaviors of others in a group setting, even when it's against our own personal beliefs or knowledge. "This is typically an unconscious process that we go through to avoid social rejection or gain status" (Gould, 2025, p.3).

Cultural bias is the bias that humans bring to their interpretation of the world due to the people, places, and things in their lives. Members of the dominant culture, which in the United States includes Whites and other people of European origin, can be and often are influenced by the values, or systems of thought, in a society that are most standard and widely held at a given time. This is referred to as the **dominant culture**. Being a member of the dominant culture with its standard and widely held values can impact one's ability to recognize

other, different systems of thought and values (Thomas & Campbell, 2017); people have been found to have more negative attitudes about those with whom they do not share identities (Hoffman et al., 2016).

A paramount consideration in health disparities research and evaluations is to do no harm to the populations involved. “Addressing bias remains a fundamental professional responsibility of those accountable for the health and wellness of our populations” (Vela et al., 2022, p. 1).

Stereotypes and Stigma

Stereotypes and biases are interrelated, often with one feeding on the other. A stereotype is “a fixed, oversimplified, and often biased belief about a group of people” (Britannica, n.d.-a, para. 1). Stereotypes overgeneralize individual attributes to entire groups of people. Some common stereotypes like “Canadians are polite” or “Asians are hardworking” are wrong but somewhat benign. Other common stereotypes like “Asian women are submissive” and “Black men are dangerous” are not benign and can be life-threatening. The problem is not just about how people react and respond to stereotyped groups, but the impact on those who are stereotyped. Referred to as stereotype threat, the theory behind it “posits that stigmatized group members may underperform on diagnostic tests of ability through concerns about confirming a negative societal stereotype as self-characteristic” (Pennington et al., 2016, para. 3). While much research has focused on the negative impact of stereotype threat on girls’ math performance and Black students’ general academic performance, it has also been found to contribute to underperformance in tasks ranging from intelligence testing to golf putting (Pennington et al., 2016). In health care, studies suggest that “stereotype threat is likely to be triggered by features in the clinical setting that make salient the stereotype of patients of color as unintelligent, “second class citizens”; and unworthy of good care” (Burgess et al., 2010, para. 5). Evaluators need to be aware of the potential impact of stereotype threat on programs and on evaluations, including participants’ responses to surveys and other measures and evaluator ratings of observations, interviews and open ended questions (Danaher & Crandall, 2008; Davis et al., 2009).

Stereotyped beliefs are characteristic of prejudice, which is an adverse or advantageous attitude toward a group or its individual members. While prejudice is an attitude, it is tied to discrimination, which is a behavior and/or an action. There are two major types of discrimination. **De jure discrimination** is that which is codified by law. While slavery might be the best-known example of previous de jure discrimination in the United States, there have been a variety of other examples, including Jim Crow laws, which made it legal to segregate Black and White people in a variety of places, such as schools, restaurants, and even restrooms and water fountains. It was even legal to have segregated hospitals where “Black Americans were often denied treatment in hospitals—sometimes because the hospitals did not have vacant “Negro beds” and sometimes because the hospitals were for Whites only” (Jim Crow Museum, 2004, para. 7).

Thanks to the efforts of many people and organizations, much of the legislation behind de jure discrimination was declared unconstitutional and/or invalidated in the United States, although recently there has been an increase in de jure discrimination, particularly for people who are LGBTQ. There is a second, often more insidious, form of discrimination, **de facto discrimination**. De facto discrimination is discrimination that is not required or allowed by law but happens in fact. Because it is more amorphous and difficult to combat legally, it is much more difficult to dismantle and is much more apt to impact evaluators and evaluations. Discrimination has real consequences for real people in real programs. For example, being in environments that are racially segregated can impact the context in which programs are implemented and the responses

of participants to programs. This must be a concern to those evaluating programs (Thomas & Campbell, 2021a). To be most effective, evaluators must be engaged in ongoing **self-reflection**, looking critically at their own biases, values, background, and experiences, and how these factors might affect their evaluations.

Table 1.2 provides an overview of six major belief systems behind much of the discrimination in the country today that impact health care and efforts to improve health care and decrease health disparities, as well as other areas.

Table 1.2 • Belief Systems Behind Oppression

Oppression	Belief System Behind Oppression
Racism	The individual, cultural, and institutional beliefs and discrimination that systematically oppress people of color (Blacks, Latinos/as, Native Americans, and Asians).
Sexism	The individual, cultural, and institutional beliefs and discrimination that systematically oppress women.
Heterosexism	The belief that heterosexuality is the only normal and acceptable sexual orientation. Encompasses the individual, cultural, and institutional beliefs and discrimination that systematically oppress lesbian, gay, bisexual, transgender, queer (LGBTQ) people, including homophobia which is an irrational fear of or aversion to homosexuality or lesbian, gay, bisexual, transgender, queer (LGBTQ) people.
Classism	The institutional, cultural, and individual set of beliefs and discrimination that assigns differential value to people according to their socio-economic class and an economic system, which creates excessive inequality and causes basic human needs to go unmet.
Ableism	The individual, cultural, and institutional beliefs and discrimination that systematically oppress people who have mental, emotional, and physical disabilities.
Ageism	The individual, cultural, and institutional beliefs and discrimination that systematically oppress young and older adults.

(adapted from National Conference for Community and Justice, n.d., paras. 12–13, 15–18; Thomas & Campbell, 2021a, pp. 11–12)

The role and impact of **stigma** is another area of concern for evaluators. Stigma is the negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency. A stigma implies social disapproval and can unfairly lead to discrimination against and exclusion of the individual (American Psychological Association Dictionary of Psychology, 2018, para. 1). It can be a factor in the recruitment, retention, and even effectiveness of programs dealing with groups who are stigmatized, such as those who are dealing with addiction or mental health issues (Crockett et al., 2025; National Institute of Drug Abuse, n.d.).

Individual biases and belief systems and biases do not exist in a vacuum. As described in more detail in Chapter 8, each individual has membership in a variety of different demographic groups, some of which are marginalized as being non-White, female or non-binary, poor or disabled. Crenshaw (2017, para. 4) named this intersectionality, which Merriam-Webster (n.d.-d, para. 1) defines as “the complex, cumulative way in which the effects of multiple forms of discrimination

(such as racism, sexism, and classism) combine, overlap, or intersect especially in the experiences of marginalized individuals or groups.”

To be most effective, health programs and their evaluation must consider participants in all their complexities, including the variety of demographic groups to which they are members and potential interactions. For example, the National Institutes of Health’s 2024–2028 *NIH-Wide Strategic Plan for Research on the Health of Women*, highlighted the biological, behavioral, social, structural, and environmental factors—and their intersections—that influence the health of women and emphasizes the need for utilization of more interdisciplinary approaches, community involvement, and innovative data science (Clayton et al., 2025, p. 29).

Evaluation and Politics

Biases influence the decisions of policymakers in government and health care as well. For example, despite extensive evaluative evidence that they were not effective, and in some cases had adverse impacts. Programs such as DARE (Drug Abuse Resistance Education) and Abstinence Only Sex Education programs continued to be funded for many years (Stanger-Hall & Hall, 2011; West & O’Neal, 2004). More recently, during COVID, the initial vaccines were available primarily for people 75 years and older, even though the data showed that the mean age of Black and Hispanic people dying of COVID-19, but not White people, was below that. “Federal public health recommendations ignored or discounted the evidence that an age-based approach would lead to further disparities in COVID-19 infections and mortality, amounting to structural racism against Black and Hispanic populations” (Vela et al., 2022, p.7). Andrews’ (2024, para. 4) conclusion that “We cannot protect our children from politics with more research, policy papers and earnest scientific explanations” (2024, para. 4) and that to make a difference, we must engage in politics, is something that evaluators need to consider as well.

Mistrust in Health Care and Government

The role of politics in health-related research and evaluation contributes to mistrust. As covered extensively in Chapters 2, there is distrust in both health care and the government, particularly among people from minoritized groups (Slatton et al., 2025). While many are familiar with the Tuskegee Study of Untreated Syphilis, where Black men with syphilis were not given treatment (Center for Disease Control, 2024c), there have been many other examples of research being conducted on people without consent or withholding findings and releasing inaccurate findings. This has, not surprisingly, led to mistrust. Interviews from Black women about their hesitancy in getting vaccines describe some of their “deep-rooted mistrust in the health care system and government.” For example:

“So, um [vaccines] actually a complete turn off to me is because of the history of vaccinations in the African American community, these were basically used as poison for us.” She added, “That’s why I’m antivaccination . . . I never like the fact that we [African Americans] are always the . . . lab experiment, the testing community for these vaccinations” (Slatton et al., 2025, p. 5).

“We heard so many conspiracy theories and didn’t know what to think,” highlighting the challenge of navigating conflicting information (Slatton et al., 2025, p. 6).

Mistrust in health care and government among minoritized groups impacts not only these individuals' participation in programs but also their participation and buy-in in evaluations of those programs.

Misinformation

Misinformation can distort public information and be a source of both stereotypes and mistrust. While there is no consensus on a common definition of misinformation, it is clear that it is information that goes against the best current knowledge. It can come from a variety of sources, including those in or representing science and medical institutions, those in for-profit, non-profit, media, and policy sectors; furthermore, misinformation can be shared unintentionally or deliberately (National Academy of Sciences, 2025). “Critically, misinformation has greater potential for influence when it originates from authoritative sources, is amplified by powerful actors, reaches large audiences, is targeted at specific populations, or is produced in a deliberate, customized, and organized fashion” (National Academy of Sciences, 2025, p. 2). It “can cause harm at individual, community, and societal levels. If someone is exposed to misinformation about science and develops misbeliefs, it may influence their ability to make informed decisions for themselves or their community, such as important choices about their personal health or how their community responds to a natural disaster” (National Academy of Sciences, 2025, p. 3). Stereotypes and assumptions behind deficit-based models can contribute to misinformation. Misinformation can also exacerbate existing harms within marginalized communities, such as worsening health disparities or discrimination.

Combatting Misinformation

Evaluators have a particular responsibility to look for and address misinformation. There are a variety of tools that help evaluators and others assess for misinformation, including the ACT UP framework in the following textbox:

ACT UP
<p>Author:</p> <p>Who wrote the resource? What do you know about them? Are they qualified to speak on the topic? What are their credentials? Can you find other works from them on the subject?</p>
<p>Currency</p> <p>When was this resource written? When was it published? Does this resource mostly contain outdated research?</p>
<p>Truth</p> <p>How accurate or true is this information? Can you verify any of the claims by looking at other sources? Are there typos, grammar errors, and spelling mistakes? Are there any words that evoke emotional responses?</p>

Unbiased

Is the information presented to sway the audience to a particular point of view?

What confirmation bias exists?

Unless otherwise stated, resources should be impartial. But, keep in mind that bias is not always bad, as long as the source is explicit about their bias and agenda.

Privilege

Are the authors the only folks who might write or publish on this topic? Who is missing in this conversation?

What are the subject terms associated with each resource you found? How are they described? Are there inherent biases?

(adapted from Stahura, 2017)

Misunderstandings, misconceptions, and mistrust are all factors that influence how evaluations are viewed and used. These can be exacerbated in times and situations of divisiveness when issues and individual words and terms are tied to controversial issues and can become “hot button,” that is they can trigger an emotional, immediate, intense reaction. When this happens, original definitions and contexts become lost or distorted. As covered in greater detail in Chapter 8 and 11, the words that are used matter. For example, when two cars are said to smash into each other, the response is quite different when the cars are said to collide (Campbell-Kibler & Campbell, 2007).

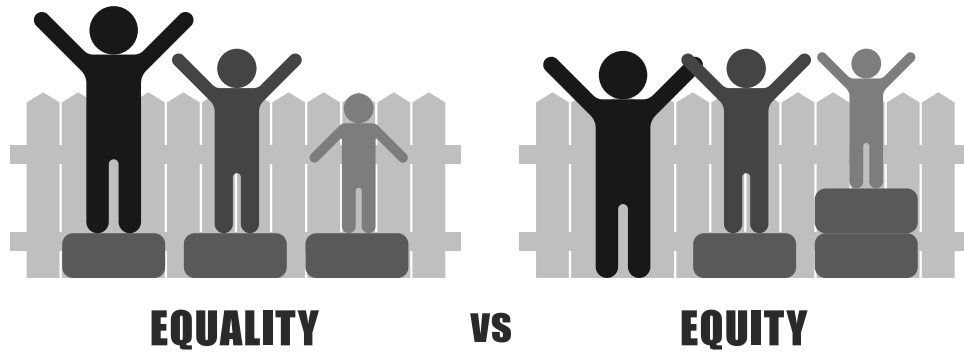
Stories and examples can influence people to change their perceptions of different words. For example, treating people equally or treating them the same way is frequently seen as the best and fairest thing to do. The following examples can help change that perception:

“You are working with two children, one of whom is a seriously overweight. The other is seriously underweight. Your goal is to bring them both to good health. Is it fair to treat them equally? Will you achieve your goal if you do so? Of course not. Fair is not always equal and equal is not always fair” (Jolly, quoted in Campbell-Kibler & Campbell, 2007, para. 8).

“Niet gelijk, maar wel gelijkwaardig—We’re not the same, but we’re worth the same” (Popular Dutch Expression).

Similarly, “while the terms equity and equality may sound similar, the implementation of one versus the other can lead to dramatically different outcomes for marginalized people... Equality means each individual or group of people is given the same resources or opportunities” (Milliken School of Public Health, 2020, para. 1-2). As the following drawing illustrates, equity recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome.

The use of contentious or hot button words or terms can unintentionally derail an evaluation. While the obvious solution is not to use hot button words, these words and their definitions can change or be changed. The same words can have very different meanings for different populations of focus. Recently terms like diversity, equity, and inclusion (DEI) and social justice have been set up and mis defined to become hot button words. While evaluators can’t make hot button words become less so, they can help different populations of focus understand the meanings and definitions of the terms. The following activity can help readers practice describing potentially hot button words for different populations of focus.



Credit: iStock.com/iam2mai

Activity: Describing Terms for Different Populations of Focus

Knowing that in many areas of the country, the words diversity, equity, and inclusion (DEI) have strong negative connotations, working with a partner, decide how, without using the term DEI, you would describe diversity, equity, and inclusion to each of the following audiences:

- a. A State Public Health Department meeting;
- b. MPH students taking a first evaluation course; and
- c. Funders.

Then, have the partner pick another audience and describe diversity, equity, and inclusion (DEI) to you. Discuss some of the similarities and differences in your presentations.

(adapted from the Alan Alda Center for Communicating Science, n.d.)

The words used influence participants, funders, readers, and other populations of focus attitudes toward the evaluation, including its credibility and relevance, and their interest in using the evaluation's findings and recommendations. These can also impact people's attitudes toward health programs as well.

Implementable Strategies and Tips

- Decide on the language you will be using when doing an evaluation
 - Ask participants their preferred name and pronouns and use them;
 - Ask the name they would prefer you use for their cultural groups and, with their permission, use those names;
 - Consider using "they, them, and their" in your writing as the singular pronoun; and
 - Use person-first language, like child at risk rather than at-risk child
- Write down one or two things that you feel should be part of any evaluation you do

- Be able to describe your evaluation philosophy in two or three sentences to
 - Program staff and
 - Participants
- Discuss with program staff strategies to deal with potential participant and staff mistrust, including
 - Spend time to meet them and learn about them and the environment in which participants and the program operate;
 - Learn and acknowledge the basis for their distrust;
 - Be transparent about the evaluation methods and goals; and
 - Share the findings with all the populations of focus
- Find a trusted informant to provide insight into the community and local politics
- Think about the content of the different chapters and identify the ones that will be most helpful in building your strengths and on remedy your weaknesses

Chapter Reflection and Application

You have been asked to meet with the overdose prevention unit of a state public health department to discuss a possible evaluation of one of their programs. Before going into details about the program and its possible evaluation, they would like you to discuss:

- your view of evaluation;
- challenges you see in evaluating a program with a population of focus that is as stereotyped and stigmatized as those with substance abuse issues; and
- how, throughout the entire evaluation process, you would deal with your personal biases.

Summarize or outline your response to each of the three areas.

Supplemental Resources

Beyond Rigor: Improving Evaluations With Diverse Populations

<http://beyondrigor.org/index.html>

This website is set up to provide easy to use tips to design, implement, and assess the quality of evaluations on programs and projects.

Misinformation Library Guide

<https://libguides.asu.edu/misinformation>

The guide includes the many forms of misinformation, evaluation frameworks to detect misinformation, statistics about misinformation, national organizations that research misinformation, and additional resources.

The Importance of Evaluating Health Disparities Research.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC6356135/>

This article describes evaluation strategies grouped into three sections: formative, design, and methodology and summative (outcomes, impacts, and cost) and describes the standards for each area, discusses its unique health disparity aspects, and provides strategies.

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- 2.4 Describe how understanding race as a social construct with biological implications, rather than a biological/genetic construct, impacts health programs and their evaluations.
- 2.5 Provide examples of how bias and inaccurate perceptions of race impact public health.
- 2.6 Identify major environmental and societal factors impacting health disparities.
- 2.7 Describe the deficit model, its impact on health program development and evaluations, and identify possible alternatives.
- 2.8 Understand the basis for minoritized communities' distrust of public health and strategies for minimizing distrust.

Introduction

There are many myths and biases tied to race and ethnicity that impact both individual and public health, as well as related programs and their evaluations. The chapter begins with an examination of what race, ethnicity, and culture are and are not, and how the concept of race is applied to Black Americans. While much of the chapter focuses on the experiences of Black people in America, the impacts of bias and discrimination on the health of Indigenous people, as well as other often marginalized groups, are covered.

The chapter defines health disparities, inequities, and equity and provides an overview of health and health disparities in the United States. It goes on to cover the various environmental and social factors that make up social determinants of health (SDOH) and their relationship to health disparities. This is followed by a discussion of how the racialization of different aspects of the health care system impacts health disparities. The chapter also includes challenges to health and health disparity programs and their evaluations, including the use of race as an explanatory factor in health disparities, the deficit model, community distrust of public health efforts and ways to deal with those challenges.

Defining Race and Ethnicity in the United States

Race, Culture, and Ethnicity

There has been, and continues to be, an overlap between the concepts of race and ethnicity. For example, the 2020 United States Census Bureau explained that “the categories of the race item include racial and national origin or sociocultural groups” (2024, para. 4). Definitions of race can be fluid, as Noel Ignatiev pointed out in his 1995 book *How the Irish Became White*. Too there continue to be questions as to whether being an Asian American constitutes a racial or ethnic identity or both (i.e., Chang & Kwan, 2009; Ruiz et al., 2023). Race is generally understood as “a sociological designation that identifies a group sharing some outward physical characteristics and some commonalities of culture and history”; while “ethnicity is a word for something you

acquire based on where your family is from and the group which you share cultural, traditional, and familial bonds and experiences with” (Merriam Webster, n.d.-a, para. 8). These definitions of race and ethnicity both include the concept of culture. However, there are almost as many definitions of culture as there are cultures themselves. While cultural groups are often defined in terms of ethnicity or nationality, “they can be any group with shared patterns of behavior and understandings such as evaluators, scientists, or even Boston Red Sox fans” (Campbell & Jolly, n.d.-b, para. 1).

One Drop of Blood Rule

While, in general, the definition and categorization of race is fluid, the situation is different for Black Americans in the United States. In the United States, a Black person is defined as anyone with any known Black ancestry. In the South, this became known as the “one-drop rule,” where a single drop of “Black blood” made a person Black. While the definition originated in the South, it soon became the nation’s standard. It is a definition that appears to be unique to the United States and applies to only one group within the United States. As Davis explained, “Not only does the one-drop rule apply to no other group than American Blacks, but apparently the rule is unique in that it is found only in the United States and not in any other nation in the world” (Davis, 1991, para. 5). Anthropologists call this the “**hypo-descent rule**,” meaning that racially mixed persons are assigned the status of the subordinate group (Davis, 1991, para. 1). Under this rule, President Barack Obama, the child of a Black man and a White woman, is defined as Black, as is reggae legend Bob Marley, the child of a Black woman and a White man.

When being Black is defined as having one drop of “Black blood,” it would be foolish to believe that being categorized as Black has a genetic or biological basis. Indeed, most scholars agree “that racism shapes social experiences and has [biological] consequences and that race is not a meaningful scientific construct in the absence of context” (Amutah et al., 2021, para. 1). Race is “a social category that reflects the impact of unequal social experiences on health” (Amutah et al., 2021, para. 1). Being perceived, or seen, as Black has an impact on health. For example, Black men who passed as White had 2.2 more years of education than their biological brothers and lived an average 9.4 months longer (Ortega, 2025). In the following activity, readers have an opportunity to reflect on what race means to them.

Activity: The Fallacy of Race as Biology

In small groups using your own experience, as well as what you’ve seen in the media or read, discuss how you judge someone’s race. How does or doesn’t that reflect conventional visible characteristics of people said to be from different races.

(adapted from Mukhopadhyay et al., 2013)

Health Disparities, Health Inequities, and Health Equity

Definitions and Distinctions

Improving the health of the public, increasing health equity, and reducing health disparities across different groups are at the heart of public health. As a concept, health disparities have been defined in various ways. For example, Jackson et al. (2020) defined **health disparities** as “an avoidable, systematic difference between socially advantaged vs. marginalized groups, where the marginalized group is further disadvantaged on health” (para. 13). In 2024, the Centers for Disease Control (CDC) defined health disparities as the “differences in the incidence, prevalence, and mortality of a disease and the related adverse health conditions that exist among specific population groups. They described these groups as characterized by gender, age, race or ethnicity, education, income, social class, disability, geographic location, or sexual orientation” (Centers for Disease Control, 2024a, para 1). Lee et al. (2020, Table 1) have somewhat different definitions. They define health disparities as “systematic differences in any measurable aspect of health outcomes due to the different distribution of social conditions across these populations” and **health inequities** as “disparities in metrics of health outcomes due to avoidable differences in social, economic, geographical or healthcare resources that are unfair and unjust.”

Health equity is more than just the absence of health disparities and inequities. While the absence of disparities and inequities is necessary, it is not sufficient to achieve health equity. As the CDC explains, “Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health” (2024b, para. 1).

Health Disparities

Mortality and Morbidity

The biggest health disparities are related to race. Almost 40 years ago, the U.S. Department of Health and Human Services published a report that put a national spotlight on the pervasive racial inequities in health. It concluded that health disparities by race accounted for more than 60,000 excess deaths each year (U.S. Department of Health and Human Services, 1985). In 2016, Hoffman et al. reported that “Racial disparities in health and health care continue to be a problem in the United States” (p. 106). Over a 22-year period, the Black population in the United States experienced more than 1.63 million excess deaths and more than 80 million excess years of life lost when compared with the White population (Caraballo et al., 2023). The Association of American Medical Colleges’ (AAMC) **amici curiae** (friend of the court) brief to the Supreme Court, authored by Heather Alarcon and Frank Trinity (2022, p. 9), concluded that there are “race-linked health inequities pervading nearly every index of human health, which combine to result in an overall reduced life expectancy for racial and ethnic minorities that cannot be explained by genetics”.

Racial disparities in Americans’ health are not just in terms of Black and White. Indigenous people in the United States have long experienced lower health status when compared with other Americans. Indigenous Americans have a life expectancy that is 6.5 years less than the U.S. population in general (Bor et al., 2025). In some states, their life expectancy is 20 years less than the national average (Indian Health Service, 2019).

The following case study describes one of the largest and most enduring areas of **racialized health disparities**.

Case Study: Health Disparities in Maternal and Infant Mortality

Maternal mortality is one of the most serious and consistent areas of health disparities. The United States has the highest rates of maternal mortality among high-income nations, with specific populations at increased risk, including pregnant people of American Indian or Alaska Native and Black backgrounds, those of lower socioeconomic status, and people younger than 18 years or older than 35 years. In 2021, more than 1,200 people died during pregnancy or up to a year postpartum, a major increase from 754 deaths in 2019 and 861 deaths in 2020. Four out of five of these deaths were preventable (Hoyert, 2023). Black mothers are three times more likely than White mothers to die from childbirth-related complications (CDC Women's Health, 2024). Significant disparities in mortality persist even when controlling for socioeconomic status, lifestyle, insurance coverage, and other factors (Tangel et al., 2019).

Similar findings are observed for infant mortality rates. In 2022, there were 20,577 infant deaths in the United States, a mortality rate of 5.61 deaths per 1,000 live births. This is a 3.3% increase from 2021. "Black non-Hispanic women's infants had the highest mortality rate, 10.9 infant deaths per 1,000 live births" (Gruppuso et al., 2025, para. 1). Infants of American Indian and Alaska Native non-Hispanic women and Native Hawaiian or Other Pacific Islander non-Hispanic women were similarly elevated. These rates are approximately twice that of Asian, non-Hispanic, Hispanic, and White non-Hispanic women (Gruppuso et al., 2025).

Other examples of health disparities include:

- Black and Hispanic children with heart conditions are more likely to die than their White counterparts (Olsen et al., 2021).
- Black men are twice as likely to die of prostate cancer than White men (Riviere et al., 2020).
- While the estimated risk of breast cancer is lower for Black women than White women with similar characteristics, Black women are 41% more likely to die from breast cancer compared with White women (Vaughan Sarrazin, 2023).
- Between 1980 and 2020, the gap in death rates between rich and poor communities grew significantly wider, with rich communities' death rates reducing while death rates in poor areas stayed relatively constant and then worsened. In 1980, people in the poorest areas were 9% more likely to die each year. Forty years later, they were 61% more likely to die (Achembach et al., 2023).
- **Socio economic status (SES)** and educational levels are predictors of health disparities; however, Black-White disparities remain even at the higher SES and educational levels although they are smaller at the higher levels (Kim et al., 2023).

Weathering

These and other disparities are tied to a phenomenon that Geronimus et al. (2006) define as **weathering**. Weathering refers to the early health deterioration that Black people experience as a "consequence of the cumulative impact of repeated experience with social or economic adversity

and political **marginalization**” (Geronimus, 2023, para. 5). “The stress inherent in living in a race-conscious society that stigmatizes and disadvantages Blacks may cause disproportionate physiological deterioration, such that a Black individual may show the morbidity and mortality typical of a White individual who is significantly older” (Geronimus, 2023, para. 5). Additionally, racism shows associations to stress exposure and reactivity as well as associations to established hypertension-related risk factors, including obesity, low levels of physical activity and alcohol use (Geronimus, 2023).

While weathering research has primarily focused on Black Americans, it has implications for other minoritized groups, particularly Indigenous people. Indigenous people in the United States have had and continue to have historical trauma in great part due to government policies which sought to “kill, annihilate, or assimilate Indigenous peoples and eradicate Indigenous culture” (Mejia, n.d., para. 1). These policies included forced relocation of entire tribes of people and coercing families to force their children to attend Native American Boarding Schools, all of which has created great historical trauma (Blakemore, 2016). This trauma, along with ongoing stereotyping and racial discrimination, lower life expectancy, and the disproportionate disease burden, places many Indigenous people at risk of weathering.

Health Care Access and Quality

Health disparities can't be discussed without understanding, as Alex Oretga (personal communication, January 29, 2025) explained that the “idea that health care is race blind disrespects the history of healthcare. Just 60 years ago, most health care in the United States was divided by race. People need to understand that when they think about health care equity and health equity, they just think about it in current times, but not thinking about the historical underpinnings of these inequities and how these systems were created and who they were created for”. The legacy of segregation, bias, and exclusion continues to adversely affect Black physicians and the patients they serve (Baker, 2008) and to impact the “socioeconomic and racial/ethnic disparities in health care quality [that] have been extensively documented” in both adults and children (Fiscella et al., 2000, p. 2579).

”Disparities in access to quality health care and any health care at all are among the factors contributing to health disparities. These disparities are often defined as differences in health care services that are not due to differences in underlying health needs or preferences” (Jackson et al., 2020, para. 13). Racial disparities in health care access and quality have been well documented in both adults and children (Goyal et al., 2015). The 2023 *National Healthcare Quality and Disparities Report* concluded that, while health care for minority group members has been improving, “significant disparities persist because White populations experienced similarly improving care” and that “people in poor and low-income households experienced worse care than people in high-income households ... The disparate measures reflected lack of access to health insurance, lack of access to healthcare services, and lack of timely access to care” (Agency for Healthcare Research and Quality, 2023, p.3). Too hospitals rated as worst based on their low quality and high cost, tend to treat higher percentages of minority patients and have higher overall costs (Jha et al., 2011).

Health care disparities are particularly acute for Indigenous people. People on reservations are served by the chronically underfunded Indian Health Service, which doesn't provide specialized services, including, in some cases, maternity care. Outside of the reservation, health care systems generally see very few Indigenous patients because it's so hard for them to access care in the private sector. A lot of the lack of access to quality health care has to do with high poverty and uninsured rates among Indigenous Americans, who also often live in rural areas with few health

care providers (Centers for Disease Control, 2024a; Indian Health Service, 2019; Whitney, 2017). About a quarter of Indigenous Americans reported experiencing discrimination when going to a doctor or health clinic (Indian Health Service, 2019; Whitney, 2017).

A lack of health insurance is a major contributor to poor health and health care disparities. People from minoritized groups are less likely to have health insurance coverage. The consequences of being uninsured are significant and include less use of preventive services, poorer health outcomes, higher disability and mortality rates, and lower annual earnings because of sickness and disease (Patil et al., 2022; Riley, 2012).

Disparities in Assessment, Diagnosis and Treatment

When people access health care, the treatment they receive has been found to differ by race. Earlier medical beliefs that the Black body was more resistant to pain and injury continue to impact medical treatment and health disparities. In 2016, Hoffman et al. (p. 4296) found that “half of a sample of White medical students and residents had false beliefs about biological differences between Blacks and Whites (e.g., Black people’s skin is thicker than White people’s skin). Those who had these beliefs rated Black patients’ pain as lower than that of comparable White patients and made less accurate treatment recommendations.” Black Americans are systematically undertreated for pain compared to Whites (Goyal et al., 2015; Hoffman et al., 2016; Mehok et al., 2023). This undertreatment holds for children as well as adults. Black children are less likely than White children to receive any pain medication for moderate pain and are less likely to receive opioids for severe pain (Goyal et al., 2015).

Disparities in medication go beyond pain medications. During the pandemic, Black patients were found to be 36% less likely than White patients to be prescribed Paxlovid for COVID-19, while Hispanic patients were 30% less likely to be prescribed Paxlovid than non-Hispanic patients (Kuehn, 2022).

Racial and ethnic differences in emergency departments (EDs) have also been found in terms of waiting times to see a physician, hospital admission rates, and management of closed head trauma (Fiscella et al., 2000; Goldfarb et al., 2023). There were even differences found in the use of physical restraints in EDs, with adult Black patients being more apt to be restrained compared with other racial groups (Eswaran et al., 2023). While Bianchi et al. (2023) are referring specifically to maternal and infant mortality rates, their comments that large health disparities are tied to differential access to high-quality care that is free from bias and discrimination hold for a number of other areas as well.

In the following activity, readers reflect on their own and others’ experiences with medical inequities. These experiences may be positive as well as negative. For example, when first author Pat Campbell’s husband was hospitalized, his treatment changed when staff learned that he was “a special friend” of a very well-respected physician who practiced in that hospital.

Activity: Health Care Inequities and You

On your own, reflect on and write down some health care inequities, either positive and/or negative, that you or others close to you have experienced. If you are comfortable doing so, in small groups, discuss your reflections.

In her Groundbreaker’s interview, Gloria Bachmann discusses how bias can impact health care providers and ways these biases can be reduced to reduce disparities in health care.

Perspectives from Groundbreakers

Gloria Bachmann: Dealing With the Ongoing Impacts of Racial and Other Biases

I believe that each team member has to examine their own prejudices; to understand their own unconscious bias so that they’re not looking at someone in a way that is going to give them substandard care rather than optimal care. This can happen when the team member considers that the person does not have a comprehensive educational background, such as with individuals who live in an underserved community. The erroneous assumption may be that because of this lack of comprehensive education, the person may not understand medical directions. And, of course, the next thought may follow: ‘therefore, I’m just not going to spend a lot of time with this person.’ Or the person from an underserved community may start asking questions and the unconscious bias may emerge, such as when the health care provider thinks, “These are not helpful questions or that this person should know the answers to them already.”

Currently, health care training includes unconscious bias training, along with the promotion of DEI (diversity, equity, and inclusion) training. But that’s not enough. If one’s assuming negative characteristics about people in different groups, then it is important that the health care trainer or mentor make that person aware of it. Everyone has to be educated about unconscious bias because so many individuals don’t realize they’re doing it.

Gloria Bachmann, MD., is an attending physician in gynecology at Robert Wood Johnson University Hospital and the medical director of the PROUD Gender Center of NJ. She is also a professor of Ob/Gyn & Medicine, the associate dean for Women’s Health and the co-director of the Women’s Health Institute at Rutgers Robert Wood Johnson Medical School. Patricia B. Campbell interviewed her in fall 2024.

Social Determinants of Health (SDOH): Environmental and Social Factors Tied to Health Disparities

Social determinants of health (SDOH) are non-medical factors that influence health outcomes. “They include the conditions in which people are born, grow, work, live, and age. SDOH also include the broader forces and systems that shape everyday life conditions” (CDC Public Health Professionals Gateway, 2024, May 15, para. 2). SDOH is of particular concern to those involved in public health because since environmental factors can influence **epigenetic** mechanisms, they can cause changes that affect the ways that genes work, which can impact future generations (Manson et al., referenced in National Academies of Sciences, Engineering, and Medicine, 2023b).

SDOH’s five major components are: educational access and quality, health care and quality, neighborhood and built environment, social and community context, and economic stability. As the Centers for Disease Control pointed out a better understanding of SDOH and how

to incorporate them into public health efforts will help strengthen public health (CDC Public Health Professionals Gateway, 2024).

There are a number of environmental and social factors linked to health disparities and general well-being. “The well-being of an individual can be thought of as an outcome of experiences with family and personal relationships, as well as interactions with many societal sectors and such systems as education, employment, and government” (National Academy of Sciences, Engineering, and Medicine, 2020, p. 2). The following is an overview of some of the most important SDOH factors.

Socio-Economic Status

Black people and people from other minoritized groups are more likely to be at lower economic or socio-economic status levels than are Whites (Creamer, 2020), and as Brady et al. (2023, p. 618) pointed out, “being in poverty is bad for one’s health.” Poverty is related to higher levels of accidents, respiratory diseases, stroke, food allergies, and air pollution. Poverty is also associated with greater mortality from violence, with people in poverty experiencing 10 times as many homicide deaths, almost five times as many firearm deaths, four times as many suicides, and 2.6 times as many drug overdose deaths (Brady et al., 2023).

Those figures were for people who were in poverty at the time of the events. **Cumulative poverty**, that is spending at least the past 10 years living below the U.S. median income, is “associated with approximately 60% greater mortality than current poverty ... Heart disease, cancer, and smoking were the only causes or risks with greater mortality than cumulative poverty” (Brady et al., 2023, p. 618).

Many of these factors are reflected in the neighborhood where people live. “A growing body of evidence has shown that neighborhoods with majority non-White residents tend to have poorer health, [which is] the result of many accumulated social and environmental inequalities such as systematic overcrowding, higher noise levels due to industrial projects, and exposure to toxic hazards” (Ortega, 2023, p. 1097).

Toxic Hazards

Polluted air is a major contributor to the unequal exposure to toxic hazards. Exposure to high levels of air pollution increases the risk of respiratory infections, heart disease, and lung cancer (World Health Organization, 2019). Racial and ethnic minorities and lower-income groups in the United States are at higher risk of premature death from exposure to air pollution than other population and income groups (Jbaily et al., 2022). “In the United States, air pollution is disproportionately created by people from the racial–ethnic majority group and disproportionately inhaled by racial–ethnic minorities. Put in another way, White Americans experience an average of 17 percent less air pollution than the amount generated by the goods and services they consume, while African Americans breathe in 56 percent more air pollution than they’re responsible for generating” (Tessum et al., 2019, para. 1).

Another toxic hazard, linked to poverty and race, is food allergies. The rate of food allergies is lowest among households in the highest income brackets. People who are Asian, Black, and Hispanic report more food allergy–related emergency department visits and more epinephrine autoinjector (EpiPen) use than White people (Jiang et al., 2023).

Living in poverty impacts mental as well as physical health. Living in poor neighborhoods, which about 24 million Americans do, is associated with higher levels of psychosocial stress and

increased risk for developing mental health symptoms even when individual and family factors are considered (Christie-Mizell, 2022; Webb et al., 2023).

Stress and Negative Social Interactions

Stress and negative social interactions can contribute to mental and other health disparities for marginalized groups, particularly those with diverse sexualities and genders. A 2020 National Academy of Sciences report concluded that the physical and mental health of sexual and gender diverse (SGD) populations are substantially affected by external influences that include discrimination, stigma, prejudice, and other social, political, and economic determinants of health. There has been work indicating that when children grow up in a context that is structurally stigmatizing toward an identity they hold, such as race or sexual orientation, that stigma can leave measurable impacts on the size of the brain's **hippocampus**, which is related to learning and memory, and other brain developmental markers (McLaughlin et al., 2022).

Housing Segregation

Residential racial segregation exacerbates health disparities. “From the choice of schools to safety to access to green spaces and healthy food, the neighborhood where a child is raised can play a determining role in their future health. Structural racism can systematically silo non-White people in certain neighborhoods” (Ortega, 2023, p.1097). This segregation results in the clustering of socioeconomic disadvantage within minority communities, whose residents are exposed to greater environmental dangers and crime, live in lower quality housing, and experience limited access to high-quality education, health care, and labor markets (Steil & Arcaya, 2023; Williams & Collins, 2001).

The following provides a summary of structural and social environmental impacts on health and health disparities.

Health Disparities and Structural and Social Environmental Impacts*

- In the United States, socioeconomic status and race or ethnicity create intersectional inequities in health access and quality (Williams).
- The consequences of lifelong stress, segregation, and discrimination result in biological weathering in underrepresented populations (Williams).
- The focus of CNS (Central Nervous System) disorder research has shifted over the past 20 years from an emphasis on unalterable genetic contributors to stroke, Alzheimer's disease, and epilepsy to thinking about how neighborhood and the built environment might affect these CNS disorders (Boden-Albala).
- Neighborhood and built environment contribute to the disparities in sleep disorders that are seen in racial and ethnic minorities (Johnson).
- Neighborhood disadvantage (such as low-income areas with reduced access to services, higher pollution, and toxin exposures) is associated with lower neurocognitive performance and lower cortical surface area in adolescence (Hackman).
- Areas that are under-resourced, such as those based in historical redlining, can endanger brain health specifically through heightened exposure to neurotoxins such as mercury and lead (2023).

*The above points were made by the individual speakers at the National Academies of Sciences, Engineering, and Medicine workshop *Addressing Health Disparities in Central Nervous System Disorders: A Workshop Series*. The names in parentheses after each bullet point refer to the speaker at the workshop who made that point.

(National Academy of Sciences, Engineering and Medicine, 2023b, p. 2)

As is the case with Black Americans, Indigenous people, including American Indians and Alaska Natives, have long experienced lower health status when compared with other Americans. Lower life expectancy and the disproportionate disease burden exist perhaps because of inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions (Indian Health Service, 2019).

Bianchi et al. (2023) concluded that the disparities in maternal and infant mortality “represent the cumulative impact of differential access to high-quality care that is free from bias and discrimination, exposure to adverse social conditions, and decreasing individual and family economic resources over the life course” (p. 1729). Those social conditions include “inadequate opportunities and access to high-quality jobs, housing, transportation, nutritious food, and safe environments” (p. 1729). Their conclusions apply to a variety of other health disparities as well.

Behind the Disparities

Racialization and Health Education

Even today, “many laypeople, scientists, and scholars continue to believe that the Black body is biologically and fundamentally different from the White body and that race is a fixed marker of group membership rooted in biology” (Hoffman et al., 2016, p. 4297). This includes many medical professionals, including medical educators, who while they acknowledge that race is socially constructed, still see race as having a genetic component (Jain et al., 2023). When instructors view race as having a genetic component, this can, and often does, impact what they teach medical students.

Most medical students have been found to believe that race is a genetic and biological construct (Vela et al., 2022). Even when they are taught otherwise, the practice of **race-based medicine** reinforces these characterizations. “Race-based medicine, the system by which research characterising race as an essential, biological variable, translates into clinical practice, leading to inequitable care” (Cerdeña et al., 2020, para 1).

When students are taught about health disparities, differences in health and health outcomes for different groups, without the historical context of systemic bias and discrimination, the “students may assume there is something inherently wrong with racialized minorities rather than with the systems that have harmed them. Students are often taught that race, instead of racism, is an independent risk factor for disease” (Vela et al., 2022; para. 20). This can lead to, for example, seeing sickle cell disease as affecting only Black people rather than seeing it as common in populations at risk for malaria, or to see cystic fibrosis as affecting White people, which can lead to overlooking it in Black patients (Amutah et al., 2021). This racialized view of diseases can limit designated populations for public health programs and impact definitions of program success. How things are named also contributes to the problem. For example, the term African

American “is a poor proxy for genetic difference, since it lumps together persons with immediate or distant ancestors from eastern, western, southern, and northern Africa despite considerable genetic differences among these populations and despite any mixed ancestry from elsewhere” (Amutah et al., 2021, p. 873). The terms Asian-American and Hispanic include similarly disparate populations. Yet we still use these terms to convey health information (Amutah et al., 2021).

Regardless of the labels or the definitions, in the United States, being Black means experiencing different and unequal social experiences than Whites. “Racism is complex and pervasive, operates at multiple interrelated levels, and exerts negative effects on other social determinants and health and well-being through multiple pathways” (Lin et al., 2021, para. 4). It shapes those experiences that can impact health and have biological consequences (Amutah et al., 2021; Jain et al., 2023).

The small number of minority physicians, particularly Black doctors, exacerbates the situation. While almost 14% of the U.S. population identifies as Black (U.S. Census, n.d.), less than 6% of active physicians are Black, with only 7% being Hispanic (Bailey, 2023). Based on history, this is not surprising. While the first Black American received an MD from an American medical school in 1857, over a hundred years later, some American medical schools still were not accepting Black students. The University of Houston College of Medicine did not accept its first Black American student until 1969 (University of Houston, 2023). Too while White women were admitted to the American Medical Association [AMA] in 1915 (Justin, n.d.), it was over 40 years later before the AMA required all member organizations to admit Black physicians (Baker et al., 2008).

A lack of diversity in the medical profession has a significant impact on the health of the public. A racially diverse medical workforce results in improved self-reported patient experiences, greater acceptance of medical recommendations, and reduced health care spending (Takeshita et al., 2020). It may also impact patient mortality. Significant reductions in in-hospital mortality were found for Black patients treated by Black physicians (Hill et al., 2020; Takeshita et al., 2020).

Racialization and Medical Equipment

Even medical instruments are not immune to racialization. For example, it has been known for 40 years that **pulse oximeters**, those gadgets people put on their finger to measure blood oxygen saturation that were widely used during the COVID-19 pandemic, tend to give less accurate results for people with darker skin (Bridger, 2022; Lipnick et al., 2025). This discrepancy has led to Asian, Black, and Hispanic patients receiving less supplemental oxygen than White patients (Gottlieb et al., 2022). As of March 2025, regulations had been drafted, but not required, that the devices work well across the full range of skin tones; consequently, manufacturers have continued making devices designed to work best on lighter skin, and clinicians and medical students have largely been unaware of pulse oximeters’ shortcomings (Lipnick et al., 2025). A second example is the **spirometer**, an instrument designed to measure pulmonary function. “First developed to support the racist assumption that Black people have less lung capacity than White people, this assumption has become so widely accepted that most commercially available spirometers used to diagnose and monitor respiratory illnesses have a **race correction** or adjustment, where the results are revised based on race, built into the software. This ‘correction’ “to control for the inaccurate belief that Black people have less lung capacity than White people makes the instrument provide less accurate results for Black people” (Hannah-Jones, 2021, p. 320). If spirometer results were used without race corrections, disability insurance benefits to Black veterans would rise by more than a billion dollars (Brainard, 2024). When developing health programs for populations with a

variety of health conditions, it is important to check if biased instruments were used to determine eligibility or to collect baseline health indicators.

Race and the Development and Use of Health Algorithms

Algorithms have been used in medicine since the 1970s to help providers make diagnostic and treatment decisions faster and more efficiently (Hirani et al., 2024). They are a set of rules to be followed in calculations or other problem-solving operations, especially by a computer (Cambridge Dictionary, n.d.-c). “By the 1990s, concerns emerged about algorithmic bias toward minoritized groups and women in general” (Jain et al., 2023, p. 1), with the result of “some algorithms run[ning] the risk of replicating and even amplifying human biases, particularly those affecting protected groups” (Lee et al., 2019, para. 4). But students still learn to “use race-based algorithms to calculate glomerular filtration rates, pulmonary function testing, hypertension guidelines, and even urinary tract infection diagnoses in pediatric populations” (Vela et al., 2022, para. 20).

“Race is included as a variable in many clinical algorithms, influencing diagnosis and treatment decisions made by physicians across the United States. However, a lack of consistency in considering race when developing clinical algorithms is negatively impacting health equity... The impact of including race in clinical algorithms can vary widely, and can be:

- Beneficial, if race is included as part of an intentional, well-considered effort to reduce inequities and it represents true biological differences based on clinical evidence;
- Neutral/have no impact; or
- Harmful, if inclusion of race in the algorithm perpetuates race-based medicine that disadvantages historically underserved populations and/or promotes the concept of innate biologic differences between racial groups that do not exist” (Council of Medical Specialty Societies (CMSS), 2023, p. 4).

Since AI (**artificial intelligence**) “utilizes algorithms to assess data from the world, makes a representation of that data, and uses that information to make an inference, it too is susceptible to bias” (Mitchell, 2021, para. 1). Panch et al. (2019, para. 3) define **algorithmic bias** as “the application of an algorithm that compounds existing inequities in socioeconomic status, race, ethnic background, religion, gender, disability, or sexual orientation and amplifies inequities in health systems.” “Algorithms in health care technology don’t simply reflect back social inequities but may ultimately exacerbate them” (Mitchell, 2021, para. 4).

There is some indication that this is happening. For example, the algorithm used to estimate kidney function (eGFR) includes a multiplier that systematically inflates the score of Black patients. Without that multiplier, more Black people would qualify for referral to a physician specializing in nephrology and more would become eligible for kidney transplants (Diao et al., 2021; Jain et al., 2023; Tsai et al., 2021). Too Vyas et al. (2019) reported that the vaginal birth after cesarean (VBAC) algorithm, which predicts the risk associated with a trial of labor for someone who has previously undergone a cesarean section, predicts a lower likelihood of success for anyone identified as African American or Hispanic. They further noted that the study used to produce the algorithm found that other variables, such as marital status and insurance type, also correlated with VBAC success; however, those variables were not incorporated into the algorithm.

In a study with even wider implications, Obermeyer et al. (2019) found that widely used algorithms used to identify and help millions of patients with complex health needs have

significant racial bias. “At a given risk score, Black patients are considerably sicker than White patients, as evidenced by signs of uncontrolled illnesses. Remedying this disparity would increase the percentage of Black patients receiving additional help from 17.7 to 46.5%. The bias arises because the algorithm predicts health care costs rather than illness, but unequal access to care means that less money is spent caring for Black patients than for White patients” (Obermeyer et al., 2019, p. 447). So, while health care cost may appear to be a good proxy for health, using it allows for large racial biases to arise (Obermeyer et al., 2019). “Continued use of race and ethnicity within algorithms may perpetuate stigma and discrimination against racial and ethnic minority groups ... Use of unreliable research could reinforce notions suggesting racial and ethnic minority groups are biologically predisposed to worse health outcomes, possibly removing motivations to tackle structural racism and other causative factors for illness” (Obermeyer et al., 2019, p. 452).

Recognizing Bias in Algorithms and Artificial Intelligence

Algorithms risk replicating and even amplifying human biases, particularly those affecting marginalized groups. Since artificial intelligence (AI) uses algorithms to assess data, make a representation of that data, and then make an inference it too is susceptible to bias (Igoe, 2021). It is difficult to know what evaluators and other researchers can do to combat those biases. As Igoe (2021, para. 9) concluded:

“There will probably always be some amount of bias, because the inequities that underpin bias are in society already and influence who gets the chance to build algorithms and for what purpose. It will require normative action and collaboration between the private sector, government, academia, and civil society.”

It is possible, and important, to ask about assumptions, to ask if there is information about the data that were used, the demographic characteristics of any population used and even the degree to which sources of the data used to generate the algorithms or to train the AI programs match the populations to which they are being applied. “Lack of diversity of both data and researchers runs the risk of creating harmful biases in the algorithms, practice, and outcome of health care data as we continue to combat health disparities and inequities faced by underrepresented and underserved communities,” said James E.K. Hildreth, president of Meharry Medical College (*Journal of Blacks in Higher Education*, 2022, para. 2). As will be seen throughout this book, program developers and evaluators who use AI need to be cautious, not just of the accuracy and completeness of AI answers, but also of the data used to train AI.

Implications for Health Disparity Programs and Their Evaluations

Using Race as an Explanatory Factor in Health Disparities

Health and health disparities are greatly influenced by a variety of factors, including social determinants of health (SDOH). However, in health program development and evaluation, data on these factors is not usually easily available, which can be problematic. Without information about environmental and/or societal factors, race and/or ethnicity may be used in decision making which can exacerbate existing disparities (Vaughan Sarrazin, 2023). Too while race and ethnicity

do not cause health outcomes, the manner in which data are presented often implies a **causal relationship**, not **correlational relationship** between race and health outcomes. As covered in Chapter 10, this incorrect assumption that a person's race is the reason for the health outcome is a major statistical misconception that can lead to important variables being overlooked. Finally, measurement of race itself is problematic. Race is typically treated as categorical, which does not reflect the diversity within communities of color or multiracial individuals (Vaughan Sarrazin, 2023, adapted from para. 3). Race and ethnicity are social constructs with limited utility in building programs and evaluations; however, they can offer a useful lens to study, view, and better understand racism, health disparities, and inequities (Flanagin et al., 2021).

Moving Beyond Using Race as an Explanatory Variable

In research on and evaluation of health and health disparity programs, it is key to consider relevant structural and social constructs, including environmental and socio-economic factors. Race/ethnicity should not be used as a place marker for those factors. If race is being used as a variable, it is important to define what race means in that context and recognize that race is a social construct that can lead to biological differences, not a genetic one. When race is misused as a proxy for other variables, such as socioeconomic status or behavioral risk factors, it can reinforce the view that race/ethnicity disparities in health stem from innate racial differences and contribute to stigma and unequal treatment of minority patients.

This doesn't mean that race shouldn't be used as a variable; it means that it should be used with a purpose. Thirty plus years ago, Betty Morrison explained:

Doing comparisons based on race is similar to taking one's temperature. You don't take your temperature when you are healthy. You take it when you are sick to see how sick you are to see if you are getting better or worse. It is the same with using race as a comparison variable. We need to do it to see what racial disparities exist and if they are getting better or worse. When there are no longer racial disparities, it will no longer be necessary to compare groups by race. (Betty Morrison, personal communication, Sept 15, 1990)

Even as a thermometer, using race/ethnicity alone is not useful. All groups are diverse. The diversity may be in terms of race, gender, ethnicity, age, geographic location, education, income, disability status, veteran status, or almost any other characteristic. It can be pretty much guaranteed that in every group there is a multiplicity of diversities (Campbell & Jolly, n.d.-a). Health program-related research and evaluation need to pay attention to the diversity of the populations being served. As will be covered in detail in Chapter 10, rather than focusing on only one demographic category, evaluations need to determine which categories are integral to the work and focus on them.

The Deficit Model

"The racialization of medicine allows doctors [and other medical professionals], societies, and individuals to blame the already marginalized and endangered for their health problems, ideas that once used to defend slavery are used to justify inequality in local, national, and global scales today" (Willoughby, 2022, p. 190). This blaming is behind the **deficit model**. The deficit model is based on the premise that deficiencies in a culture are the cause of differences between minority group members and members of the **dominant group** (Thomas & Campbell, 2021a). Biases and stereotypes about which or whose **cultural mores** (social or cultural rules) are seen

as the norm, the right way, or even the only way, fuel the development and use of the deficit model in program development and evaluation. “Evaluators must be wary of deficit models that, essentially, blame individuals for social problems, rather than consider how institutional practices or societal responses to certain individuals or cultural groups place them at increased risk for negative outcomes” (Thomas & Madison, 2010, p. 571). For example, deficit models assert that the higher mortality rates of Black women and infants are tied to dysfunctional family cultures and/or individual behaviors that do not reflect characteristics that are considered important to the White American culture (Campbell et al., 2022; Carpendale et al., 2008). In this model, pregnant women of color are seen as lacking in some ways, as needing to be fixed and needing to develop skills and behaviors valued by the dominant culture (Campbell & Thomas, 2021a). Policies that view “pregnant people themselves as the greatest threat to fetal life” are an example of a deficit model, which does “nothing to address factors that play a far greater role in infant and maternal mortality, including lack of access to healthy food, clear water, safe housing and medical care” (Crowther, quoted in Mulder, 2023, p. 524). As this example indicates, when programs are designed to fix individual weaknesses/inappropriate behavior as defined by the dominant culture, without looking at the context or the broader environment or the individuals’ strengths or potential differential treatment or discrimination, they are, by definition not addressing issues in their complexity and are condemned to have limited success and may even be counterproductive.

Programs focusing on people with disabilities can be at risk of defaulting to the use of deficit models tied to disability. The Medical Model of Disability is familiar to the general public. It views disability as an individual problem caused by disease, trauma, or another health condition. The assumption is that the defined problem requires sustained medical care with the goal of a ‘curing’ or an individual’s adjustment and behavioral change that would lead to an ‘almost-cure’ (Langtree, 2025). A model of disability that is particularly damaging and is fortunately less prevalent today is the Moral Model of Disability, which holds people morally responsible for their own disability. Some cultures still associate disability with sin and shame for both the person with a disability and their family, which often leads to guilt, isolation, and ostracism. Another model that has been good for raising money but not helpful for self-determination is the Tragedy and/or Charity Model where people with disabilities are seen as victims of circumstance, deserving of pity. Under these models, the problems associated with disability are seen as individual problems with society having no underlying responsibility to make a place for persons with disabilities (Kaplan, n.d.; Langtree, 2025; Retief & Letosa, 2018; Thomas & Campbell, 2021a).

The following activity provides readers with an opportunity to further explore deficit models.

Activity: Read, Reflect, and Discuss: Identifying a Deficit Model

Read the following description and in small groups discuss if this represents a deficit model and why or why not.

“During a White House coronavirus task force briefing, Dr. Fauci, [then] director of the National Institute of Allergy and Infectious Diseases since 1984, stated, “Health disparities have always existed for the African American community ... [coronavirus is] shining a bright light on how unacceptable that is because, yet again, when you have a situation like the coronavirus, they are suffering disproportionately. We will get over

coronavirus, but there will still be health disparities which we really do need to address in the African American community” (Ray, 2020, para. 5).

Ray (2020, paras. 6-7) pointed out factors counter to the deficit model that Dr. Fauci appeared not to be considering in his statement:

“I argue structural conditions that inform pre-existing conditions and health disparities are the main culprit for the epidemic within the pandemic which is ravaging Black communities across the U.S. A decade ago, I worked as a Robert Wood Johnson Foundation Health Policy Research Scholar at the University of California at Berkeley. I conducted research on obesity and physical activity and discovered that health outcomes are as much about place as they are about race—the racial compositions of neighborhoods to be more specific.

Blacks are more likely to be part of the new COVID-19 “essential” workforce. Blacks represent nearly 30% of bus drivers and nearly 20% of all food service workers, janitors, cashiers, and stockers. During a highly-contagious pandemic like COVID-19, Black workers, and consequently their families, are over-exposed.”

Structural inequities and discrimination have created stereotypes of marginalized populations or communities and implicit and explicit biases toward them. “The cumulative effect of overrepresenting minorities as high-risk is the creation of an implicit link between race and predisposition to disease, which reinforces the view that race/ethnicity disparities in health stem from innate racial differences. This representation contributes to stigma and unequal treatment of minority patients, concretizes race-based hierarchies, and obfuscates the role of racism in producing health outcomes” (Amutah et al., 2021, para. 8). Health care providers can hold negative explicit and implicit biases against racialized minorities. A similar reinforcing dynamic may exist for marginalized populations such as those who are overweight/obese, have disabilities, have limited English proficiency, have a mental health illness, and/or are lower income (Vela et al., 2022).

Alternatives to the Deficit Model

As will be addressed in detail in Chapter 5, there are powerful alternatives to the deficit model. “The narratives and analyses of sorrow, pain, tragedy, and inequity in health equity research tell only part of the story of what it means to be Black in the United States. There are many other stories to be investigated and reported, stories of Black people’s strengths, assets, resistance, and joy, even in health inequity research. What is the good stuff? What is protective? On what resources do Black communities ... draw despite injustice and inequity? Which strengths are harnessed for resistance and when?” (Bowleg, 2021, p. 241). The use of **strength-based models** are viable, more effective alternatives to deficit models. They are used when program developers and/or evaluators and other researchers are aware of systemic and contextual factors and look at participants from a strength perspective which values the capacity, skill, knowledge connections, and potential in individuals and communities while not ignoring the challenges or spinning struggles into strengths (Parker, 2004).

In an alternative to the deficit model, “the National Institutes of Health (NIH) launched the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) ... to integrate biological, behavioral, social, and structural factors to build an evidence base for improved care and outcomes in specific populations and regions of the country” (Bianchi et al., 2023, para. 2). There are alternative models related to people with disabilities as well. The **Social**

Model of Disability Model (Oliver, 1996) views “disability” as a socially created problem, that is, what makes someone disabled is not their medical condition, but the attitudes and structures of society. In other words, this model argues that social discrimination is the most significant problem experienced by people with disabilities and is the cause of many of the problems that are regarded as intrinsic to the disability under the other models (Retief & Letosa, 2018). Another model, the **Empowerment Model**, focuses on having the person with a disability and their family, rather than the medical community, decide the course of their treatment and what services they wish to benefit from, thus turning the professional into a service provider whose role is to offer guidance and carry out the client’s decisions (Kaplan, n.d.; Langtree, 2025; Retief & Letosa, 2018; Thomas & Campbell, 2021a).

Medical Trust and Mistrust

Causes of Medical Mistrust

Perhaps the best-known example of racism in medical research in the 20th century is the Tuskegee study of untreated syphilis, described below.

The Tuskegee Study of Untreated Syphilis

From 1932 until the Associated Press broke the story in 1972, the U.S. Public Health Service conducted a study of more than 600 Black men, 399 of whom had syphilis. Researchers advertised for “colored” participants with the slogan “Last Chance for Special Free Treatment” by the Macon County (AL) Health Department and government doctors. They never obtained informed consent from the men and did not inform the men with syphilis that they were not being treated but were simply being monitored and left to suffer with syphilis long after a cure (penicillin) became available in 1947. The study ended only when the Associated Press broke the story about it in 1972. At that point, only 74 of the men were still alive (Cunningham, 2022; Thomas & Campbell, 2021a). John Heller, chief of the Division of Venereal Diseases at the U.S. Public Health Service from 1943 to 1948, concluded that “the men’s status did not warrant ethical debate. They were subjects, not patients; clinical material, not sick people” (Cunningham, 2022, para. 7). This contributed to the distrust of medical institutions that many African Americans still have (Cunningham, 2022).

While the Tuskegee study is well known, there are many other cases. In St. Louis, Missouri, in the 1950s and 60s, men in protective suits regularly sprayed a mysterious mist from the tops of buildings and from vehicles driving through predominantly Black neighborhoods. It wasn’t until 1994 that the U.S. government acknowledged that they had been spraying a chemical, zinc cadmium sulfide, as part of a military experiment (Goodwin, 2021). An Army commissioned study later asserted that the experiment did not harm the health of people in St. Louis in the short term, and studies of its toxicity on rats and dogs concluded it was “practically” nontoxic. However, no studies were conducted on the longer-term effects on humans; nor was there any analysis of possible chronic health problems among the people who lived in the area where the spraying was conducted (Goodwin, 2021; National Research Council, 1997).

In another example, in 1956, as part of a Cold War secret military program called Operation Big Buzz, which to test the viability of deploying mosquitoes as a delivery system for disease

warfare, dropped thousands of mosquitoes on a Black neighborhood in Savannah, Georgia, and later at a bombing range in Florida. In 1980, the **Army Chemical Corps** released a report stating that the mosquitoes were not infected with yellow fever. The program's secrecy and the 24-year delay in the release of the report had some Savannah residents questioning whether the mosquitoes really were uninfected (Associated Press, 2021; United States Army Chemical Corps, 1959).

Beginning with the National Research Act of 1974, the Tuskegee Study served as a catalyst for strengthening the protection of human subjects in federally funded research. However, the effects of such unethical research persist. For example, Alsan and Wanamaker (2018) reported that the 1972 disclosure of the Tuskegee study was correlated with increases in medical mistrust and mortality and decreases in both outpatient and inpatient physician interactions for older Black men. Additionally, research efforts, such as Operation Big Buzz, may have contributed to greater Black resistance to getting the COVID-19 vaccines. As Savannah resident and activist Natavia Sanders explained:

“This has been the only system of America that American descendants of slaves know, and therefore there are automatic cautions to survival,” Sanders said. It only makes sense for Blacks to question vaccines and studies, she said, after “countless times of being the study (subject) for things without their consent or knowledge (Associated Press, 2021, paras. 4-5).

The fact that there is a lower-than-average rate of Black volunteers in clinical studies is not surprising considering the distrust engendered by activities such as those described earlier. However, Black participants were 12.6% more likely to express a willingness to participate in a medically related study if the principal investigators (PIs) or lead researchers were Black. Black participants also rated pictures of Black PIs as more trustworthy than those of White investigators (Science News Staff, 2023, October 13). Black Americans are not the only minority population who distrusts the health care system. The combination of historical trauma, a severely underfunded Indian Health Service (IHS) that doesn't provide specialized care, experiences of prejudice and discrimination when seeking health care both within and outside of reservations, along with knowledge of the forced sterilization of thousands of Indigenous women by the IHS, have contributed to Indigenous people's deep distrust not just of the IHS but other the medical care system in general (Blakemore, 2016; Mabie, 2024; Whitney, 2017). As indicated in Table 2.1, there are many others marginalized groups and/or those having little power over unethical research conducted on them.

Table 2.1 ■ Examples of Unethical Research Done on Marginalized/Less Powerful Populations

Study Content	Years	Population	Description
Radiation	1940s-early 50s	Hospital patients, pregnant women, children with intellectual disabilities, and enlisted soldiers	Without their consent or even knowledge, people were being exposed to radioactive materials to study their effects (Pacchioli, 1996; Thomas & Campbell, 2021a).

(Continued)

Table 2.1 ■ Examples of Unethical Research Done on Marginalized/Less Powerful Populations (Continued)

Study Content	Years	Population	Description
Mustard Gas	1940s-early 50s	Enlisted soldiers	60,000 Americans were exposed to mustard gas, with about 4,000 of these soldiers being subjected to severe, full-body exposures on contaminated ground areas (Love, 2015.; U.S. Department of Veterans' Affairs, n.d.; Woodruff, 2015).
Birth Control Pills	Mid 1950s-1964	Women in Puerto Rico	In the mid-1950s, the first large-scale human trial of the pill was launched in a public housing project in Puerto Rico, where as many as 1,500 women took the drug over several years. The drug had been tested on rats and rabbits and on a small sample of women in Massachusetts (Vargas, 2017).
Hepatitis	1956-1971	Children with intellectual disabilities	Children at the Willowbrook State School for Children were deliberately infected with live hepatitis to study different strains of hepatitis (DuBois, 2008).
Following Orders	1971	Male college students	In the Stanford Prison Experiment, students were assigned to play the role of prisoner or guard in a study of prison life. The "guards" became so abusive to the "prisoners" that the experiment had to be stopped (Stanford Prison Experiment, n.d.).
Following Orders	1963	College students	Known as the Milgram experiment, participants were led to believe they were causing severe pain to another person by administering electric shock. Some participants became very upset and asked for the experiment to be stopped, but the researcher in charge insisted they continue, causing great emotional distress to some participants (Herrera, 2001; Thomas & Campbell, 2021a).

In the following activity, readers will read about an experience with distrust of the health care system and reflect on ways to deal with that distrust.

Activity: Read, Reflect, and Discuss: Understanding Distrust

In the early 1970s, I, Pat Campbell, the first author and a White woman, went to a doctor's office in Mississippi with two other women—one Black and one White. There were two waiting rooms—one for Whites and one for Blacks. As an interracial group, we were told

we could separate or go to the Black waiting room. I, a visitor to Mississippi, said, “We need to protest this.” The other two, both local civil rights workers, said “No—we don’t protest at doctors’ offices because when the doctor gives you a shot, you never know what is in it.”

In small groups, discuss this story and the reasons behind the distrust that many Black people and others have of the medical establishment, research, and evaluation. Then, explore possible ways to share your understanding of that distrust with others and possible ways to reduce distrust.

While there have been a number of examples of biased and unethical treatment of minoritized groups in the health care system, there have also been a variety of efforts to increase health equity. These include the establishment of the Public Health Service in 1798, the establishment of Medicare and Medicaid in 1965 and the passage of the Americans with Disabilities Act in 1990.

Building Trust Among Marginalized Groups

Historical and current discrimination, stereotyping, and awareness of unethical research done in their communities, in some cases fatal, has fueled a deep distrust among many Black people of the medical establishment and of medically related research. This distrust can impact individual participation in health-related programs and in program evaluation and research. Chapters 5 and 7 will go into detail about a variety of ways to build trust and engage groups in health-related programs, as well as in program evaluation and research. It is key for evaluators and researchers, as well as program staff, to acknowledge past and current incidents and institutions that have generated distrust and to be transparent in program goals and activities and the participants’ benefits, responsibilities, and possible risks. Taking time to know, and be known in, participating communities and working with trusted community leaders and institutions can make a difference. Much can be learned from successful community and other efforts to increase confidence in the COVID-19 across Black communities. These include:

- Acknowledge that systemic racism has contributed to an understandable and justified response of mistrust before providing information about the vaccine.
- Develop clear, layperson-oriented, transparent messaging that (a) is tailored to specific subcommunities within the broader Black American community and (b) acknowledges both what we know and what we do not know about the vaccine, particularly when conducting outreach to marginalized subcommunities, such as people living with HIV, sexual minorities and gender minorities, and immigrant communities.
- Provide opportunities for open dialogue with scientists and health care providers who can answer questions.
- Identify trusted messengers . . . including trusted public health officials and Black doctors, who can work with local leaders to disseminate information together.
- Leverage the power of social networks, including friends and family who have been vaccinated, who can discuss their vaccination experiences and reasons for getting vaccinated with their peers (Bogart et al., 2021, para. 7).

In his Groundbreaker's interview, Bob Fullilove discusses how he helps his Columbia University Masters of Public Health students build trust in the Dominican and Black communities in which they work.

Perspectives from Groundbreakers

Bob Fullilove: Overcoming Distrust

I told them that there are people in the community who exist just to be community organizers—find them, partner with them. If they accompany you as you walk into a room, if they introduce you as a friend of the program, that's your way in. That's what I've done.

I have people imagine themselves as being neighbors, as being members of a community and part of the populations that they're working with, as opposed to being folk who are outsiders who are coming in bringing in White man science to change the life of the natives. That readjustment means that in a lot of instances people have to give up the arrogance that comes from their education and accept the fact that sometimes you're in a community where somebody with a third of your education has more to say and has more relevance.

Robert E. Fullilove, EdD is the associate dean for Community and Minority Affairs, professor of Clinical Sociomedical Sciences, and the co-director of the Cities Research Group. Columbia University Medical Center. Patricia B. Campbell interviewed him in winter 2025.

Implementable Strategies and Tips

- Don't use race/ethnicity as the only factor in a program or its evaluation
 - If using race/ethnicity, have participants self-identify their own race/ethnicity
 - Break down broad racial/ethnic categories such as Hispanic and Asian American into subcategories
 - Learn what other demographic characteristics are important to groups of focus
- Explore potential unaccounted SDOH variables that may be impacting health disparity programs and their evaluations
 - Review Census and other sources of demographic variables within the areas of focus
 - Learn about environmental issues with the communities of focus
- Learn more about the causes of members' of minoritized groups' distrust of the health care system
 - Read about historical trauma and Indigenous people. The American Indian Health and Family Services Resource Guide is a good starting place
 - Learn more about racism in U.S. health care. Health Affairs offers a short overview. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01466>
- Select or generate some strategies for dealing with people's distrust that you would feel comfortable using
 - Discuss with members of populations of focus other possible strategies
- Reflect on your own stereotypes and biases
 - Check to see any negative assumptions you may have about people in different groups

- When reading proposals or program descriptions, check to see if deficit models are a part of their design or underlying assumptions
 - Consider alternative strength-based models that could be used instead
- Be critical about the use of artificial intelligence (AI) based algorithms
 - Ask about how the algorithms were developed
 - Determine the populations over which they were developed and/or the materials that were used to train them
 - Review the results of any use of AI

Chapter Reflection and Application

You have been asked to do a three-hour workshop for new Masters of Public Health students on bias, discrimination, and racism in the health care system.

- Decide on a goal for your workshop.
- Make a list of the topics that you would include in the workshop and why you chose them.
- Write down the impact you hope the workshop will have on the students.

Supplemental Resources

Agency for Healthcare Research and Quality (AHRQ)

<https://www.ahrq.gov/>

AHRQ reports on progress and opportunities for improving health care quality and reducing health care disparities. The National Healthcare Quality Report (NHQR) focuses on “national trends in the quality of health care provided to the American people” while the National Healthcare Disparities Report (NHDR) focuses on “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations.”

Confronting Racism in Health Care: Moving From Proclamations to New Practices

<https://www.commonwealthfund.org/publications/2021/oct/confronting-racism-health-care>

This report focuses on providing strategies for combating racism in health care.

Reconsidering Race in Clinical Algorithms: Driving Equity Through New Models in Research and Implementation

https://cmss.org/wp-content/uploads/2023/11/11279_CMSS_Report_FINAL.pdf

This report describes issues tied to the lack of consistency in considering race when clinical algorithms are developed, which is negatively impacting health equity.

Taking Steps Toward Anti-Racist Health Care

<https://harvardpublichealth.org/policy-practice/taking-steps-toward-anti-racist-healthcare/>

The site highlights notable efforts to increase equity and reduce bias in clinical trials, medical education and practice, and other areas of health, from across the United States.