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The Social Transformation of Health Inequities: Understanding the Discourse on Health Disparities in the United States

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The Social Transformation of Health Inequities: Understanding the Discourse on Health Disparities in the United States

By

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DISSERTATION

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Requirements for the Degree of

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Dedication

To Janice Kando, partner and best friend, whose continued love and support always encourages and nourishes me

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ABSTRACT

Discourse in the United States characterized “health disparities” as the disproportionate burden of morbidity and mortality suffered by racial, ethnic and other disadvantaged populations. This dissertation contributes a theory of social construction that transformed health inequalities and inequities into “health disparities,” a hegemonic (dominant) concept that prevented structural analysis of root causes and effective solutions. Consequently health disparities remain.

My study focuses on the discourse during the latter part of President Clinton’s administration (1999-2001), when eliminating “health disparities” became a major objective. Anchored by hegemony and racial formation theories, and using critical discourse analysis as the principal research method, I study the social construction of “health disparities.“ I also discuss the differences in discourse between the United States and other countries. I analyze a selection of official government reports published between 1979 and 2010 and interviews with a sample of key informants involved in policy and/or academia at the time of the study. In addition I perform limited quantitative content analysis to look at the change in use of the term "disparities" through time.

I find that the discourse on "health disparities" emphasized race and ethnicity, individual responsibility, and medical care. This narrow focus omitted and diverted attention from root causes such as growing structural inequality, thus exculpating government of responsibility and forestalling socio-economic change. My analysis suggests that, because of their elite positions and qualifications, individuals who contributed to the discourse in government participated in transforming health inequities into "health disparities."

This study contributes to sociology, population health and social epidemiology by applying racial formation theory to the study of health inequalities and inequities, and extending its principles to class formation; thus, it adds a greater understanding of the social construction of health inequities, as affecting racial and ethnic minorities, as well as other disadvantaged populations. My study also helps make sense of how hegemony operates at the individual and institutional levels. Through omissions, contradictions, fears and capitulation, individuals who express passion and desire for social change and eliminating inequities in society contribute to maintaining the status quo by diverting attention from more fundamental transformations in inequities and inequalities.

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Chapter 1: Introduction

"On February 21, 1998, President Bill Clinton announced a new initiative that set a national goal of eliminating longstanding racial/ethnic disparities in health status by 2010. The President proclaimed that the federal government would, for the first time, set high national health goals for all Americans, ending a practice of separate, lower goals for racial and ethnic minorities."[1]

"Eliminating racial/ethnic health disparities" and "ending a practice of lower goals for racial and ethnic minorities" were landmark pronouncements in the history of efforts to equalize the health outcomes of minority populations. Together with "the Minority Health and Health Disparities Research and Education Act in 2000 (Public Law 106-525, 106th Congress)[2] that elevated the existing NIH "Office" of research on minority health to "Center" status, the mechanisms for correcting disparities in health based on race and ethnicity appeared to be in place. President Clinton had a Democratic Party majority in Congress and the House, the Black Caucus was strong, and there were prominent black leaders in the administration such as Dr. David Satcher, Surgeon General and Assistant Secretary of Health and Human Services. Looking back, we find that recognition by the federal government of health gaps between blacks and whites was not new, and that the road to 'eliminating' health disparities had been paved at the federal government level, in this most recent iteration, since at least 1979[3].

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[1] Press Briefing. Accessed at http://www.presidency.ucsb.edu/ws/index.pHPR?pid=48378

[2] Public Law 106-525, may be accessed through Thomas, Library of Congress, 106th Congress

[3] National concern over health disparities has been expressed for several decades. Examples include the 1979 U.S. Department of Health, Education, and Welfare report, The Health Status of Minorities

Moving forward to the present (2012) we know that the health of racial and ethnic minority populations, the poor, and other socio-economically disadvantaged groups continues to vary considerably as indexed by excess mortality, morbidity, and shorter life expectancy. These “health disparities” are a source of great and avoidable suffering for millions of individuals, and of shame to the nation. Yet in spite of continued and extensive research, numerous policies, programs and money targeted to the problem of ‘health disparities,” they persevere. I became interested in investigating how the gaps in health between different groups (racial, ethnic, economic and other disadvantaged groups) have been conceptualized in research and policy. I argue that definitions guide discourse, research questions, measurements, policies and interventions that can either reduce - and even eliminate - disparities or exacerbate them.

Thus my dissertation maps the social and intellectual history of how the term ‘disparities’ (mere differences) came to replace ‘inequalities’ (preventable, avoidable differences in outcomes) and ‘inequities’ (preventable, avoidable, and unjust differences in resources) in health in the United States with an exploration of the background for the phenomenon at the global level. While the linguistic and conceptual change may appear to be only semantic, it, in effect, dilutes - if not erases - social justice and equity principles that had earlier guided the narrative and

---

and Low-Income Groups (Health Resources Administration, 1979); the 1979 Healthy People report (U.S. Public Health Administration, 1979); the 1986 Report of the Secretary’s Task Force on Black and Minority Health (U.S. DHHS, 1985); the Healthy People 2000 report (U.S. DHHS, 1991), which listed the reduction of health disparities as one of three goals; and the Healthy People 2010 report (U.S. DHHS, 2000), which had the elimination of health disparities as one of its two goals. Accessed at http://www.ncbi.nlm.nih.gov/books/NBK57058/

work on the social determination of health. I trace and analyze the events leading to the disparities narrative between the late 1990’s and the early 2000’s, and the much longer intellectual history that led to the most recent social and political construction of health disparities. I aim to advance the sociology of the conceptualization of health disparities particularly regarding the social construction of race and class.

An exploratory review of the literature and government documents reveals that the prevailing rhetoric of *health disparities* was initiated in the United States in the 1990’s and solidified under the Clinton administration in the Surgeon General’s report (Satcher, 1999). Interestingly, other countries and international bodies such as the World Health Organization did not use the “health disparities” concept (As an example of the difference in discourse I will use the World Health Report 2000 (WHR 2000), published by the World Health Organization (WHO) and directed by Julio Frenk and Christopher Murray. Academics and government representatives from several countries vigorously debated the approach and methods in the WHR 2000 and published timely critiques (e.g. Almeida, et al., 2001; Braveman, Starfield, & Geiger, 2001; Deber, 2004; Hakkinen & Ollila, 2000; Hollingsworth & Wildman, 2000; Navarro, 2000; Cruz O. Foundation, 2000; and Uga, Szwacwald, Almeida, et al., 2000). Murray and Frenk and other WHO personnel published responses to the critiques (Gakidou, Murray & Frenk, 2000 a & b; Murray & Evans 2003; Murray & Frenk, 2001).

The critiques and scrutiny of the World Health report seemed effective in provoking changes in the WHO’s approach. By 2003 equity and justice values in relation to health were espoused by the new director of the WHO (Lee, 2003) who stated new interest in the social determinants of health and adherence to principles of equity and social justice and initiated the Commission on the Social Determinants of Health. However, in the United States, up to 2011, organizations like the National Institutes of Health (NIH) continued to instruct applicants for research funding based on a disparity definition that privileges individual responsibility over social determinants that are, for the most part, beyond the control of individuals (Braveman, 2006; Brown et al., 2006, Fielding, 1999). The US position contrasts with the United Kingdom's where "All health differences between the best-off and the worst-off in different socioeconomic groups [constitute] inequities in health" (Bambas & Casas, 2001, p.16).

My study aims to clarify how health disparities were constructed, including identifying the agents instrumental in the change and the interests served. Like all stories, this one presents several sides depending on the storyteller and the perspectives of its makers. The history of the disparity definition will bring to light the underlying beliefs and values guiding the dynamics that contributed to manufacturing reality and consent about the definition of health disparities. Story details will highlight agency and how it is used for political purposes. Contextualization of the story within a social and political environment will aid in clarifying the forces that, in this project, led to a definition that has dominated the discourse and the politics of health.

Research Question and Significance of Project

"How was the social construction of health disparities among racial and ethnic minorities and other disadvantaged populations accomplished and implemented?"

Theoretically, I will focus on the social and intellectual history that led to the replacement, at a particular moment in history, of the terms and concepts ‘inequities’ and ‘inequalities’ with the term ‘disparities’ and its adoption and use in political and academic discourse. Empirically, I will analyze a selection of official government documents that promulgated the policies and served as basis for program implementation, and will report the results of interviews with key informants, such as policy makers and academics that were involved in the development of the disparity definition and formulation of consequent health policies.

New literature recognizes that knowledge about the determinants of health has not translated into effective policies that improve health disparities (Braveman, Egerter & Williams, 2010, among others). Bodies like the Commission on the Social Determinants of Health – established in 2005 – have discussed strategies to close the gap between knowledge and action (Irwin & Scali, 2011; Pega, Valentine & Matheson, 2011; and Solar & Irwin, 2011). There is, however, scant sociological analysis of how the political economy succeeded in constructing health without an equity framework. My study engages in this analysis to elucidate how the change from inequity to disparity was made possible; how the social and political process that changed the discourse set a trajectory of health policy and action devoid of principles of fairness and social justice; and how the disparity definition dominated and prevailed in theory and practice in the United States.

To the best of my knowledge the type of sociological analysis proposed has not been done in the United States or elsewhere. I aim to fill this gap in the sociology literature. This study will shed light on how the policy and programs in health can occur, apparently without much public debate, and yet, with far- reaching consequences. The study might caution researchers in the health fields, including medical sociology, to be more mindful of the effects of the political discourse on research agendas and narratives; and it might encourage racially and socially stigmatized populations – such as Blacks, Latinos, and poor Whites, among others - to question the implications of considering all disparities the same.

In the United States, separate from international trends, the consequential change to “disparity” has been adopted by researchers and society in general. The disparity discourse, thus, has permeated and dominated health policies since its inception, with little public contestation. Considering the pervasive history of discrimination that systematically places people of color, the poor and other groups subject to economic and social deprivation at a disadvantage in many areas, including health, there are definite problems with the disparity language/concept, what it measures, and its consequences for the health of the population (Krieger, 1999).

This research aims to make the links between the micro level (discourse) and the macro level (structures of government) through the meso level (societal institutions) that allowed the dominant social construction of health disparities. The study might spur changes in research and ways to translate it into policy that will potentially benefit the health of underrepresented populations in the United States. It may also add a note of caution to researchers who may, unquestioning and/or uncritically, accept and follow the dominant language of policy dictated by the demands of the economic system, in effect forgetting what has long been known about the effect of socio-economic conditions on health. And, it may help underrepresented communities prevent or counteract policies that perpetuate health inequalities and inequities, by understanding how those policies are made, and how consent is constructed so they become hegemonic (dominant in spite of negative consequences for the population).

Understanding why the discourse on the social determinants of health has developed without an applicable social justice component will also aid in the translation of knowledge into practice (policy and interventions) to remedy health inequities. I will start with definitions that highlight the differences among the concepts of disparities, inequalities and inequities in health as a prelude to the conceptual development undergirding this study.

Definition of Terms

Disparities, Inequalities and Inequities

The terms disparities (mere differences), inequalities (preventable differences in outcomes), and inequities (preventable and unjust differences in resources) are often used indiscriminately as if they meant the same thing, and as if there were consensus about their meaning. Understanding the differences in meanings is more than an intellectual exercise when used in reference to the study of health because different meanings lead to different research questions, measurements, methods and interpretations; in turn these meanings lead to different policies and interventions, and therefore different consequences for health. Clear definition of terms is necessary to understand the development of the disparities discourse and its dominance in politics and academia in the United States. Curiously, the term ‘health disparities” is mostly used in the United States and the terms ‘health inequity’ and ‘health inequality’ are used in other countries (Carter-Pokras & Baquet, 2002). However, the definition of “disparities” in the United States can mean different things depending on who is using it. In their investigation, Carter-Pokras and Baquet (2002) identified 11 different definitions[4] used by different agencies, which made it difficult to agree on measures to compare populations.

Health Disparities. Based on discussions by Braveman (2006) and Krieger (2001), and Carter-Pokras (2002), and on definitions appearing in government documents, “health disparity” is a descriptive term, mostly used in the United States, to denote health differences between racial and ethnic populations. Often these differences are ascribed to individual behavior, culture or genetics and not to social disadvantage; therefore the differences become the responsibility of individuals and not of the state. Consequently, when differences in health between populations are defined as disparities, common interventions concentrate in efforts to change individual behaviors, not social conditions. Research questions based on *disparity* as defined above, for example, would include: What are the reasons for disparities in obesity rates between Whites and individuals in different racial/ ethnic groups? This question would lead to the study of individuals as the unit of analysis, and to interventions such as diet and nutrition programs. In a way, this approach tends to

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[4] Carter-Pokras and Baquet, 4 years after president Clinton’s announcement of the goal to eliminate health disparities, found different definitions by the Department of Health and Human Services, ”Healthy People 2010,” Washington State Board of Health, Health Resources and Services Administration, National Institutes of Health, and Institute of Medicine.None of these definitions implied more than differences, or referred to causes for the differences.

blame the victim, does not get at root causes, and does not lead to effective solutions. The term health disparities has become the most commonly used to refer to the persistent unequal distribution of health in the United States since the latter part of the twentieth century (Ibrahim, Thomas, & Fine, 2003). However, it does not connote the complexity of societal conditions that mediate opportunities for health for different social groups.

Health inequalities. Inequalities in health refer to preventable, avoidable differences in health outcomes between better-off and worst-off groups, linked to socioeconomic conditions or similar social determinants (Braveman, 2006). Inequality is considered a dimensional concept, referring to measurable quantities, usually including measures of education, income and occupation. An inequality definition would lead to a question such as “Why is obesity more prevalent among poor people or Black people?” The answer may point to the lack of good supermarkets offering affordable, healthy foods in poor or racially segregated neighborhoods, and the solution may involve communities’ working with leaders to attract better supermarkets, a meso level solution involving local institutions (Beckfield & Krieger, 2009; Braveman, 2006; and Whitehead, 1990). While this definition leads to broader considerations than the disparity definition, in many studies it downplays other conditions such as absolute poverty, racism, hunger, inadequate housing, and poor education, which are macro-structural in nature (e.g. Kawachi et al., 2002).

Health inequities. Inequities refer to structural differences that are “systematic, patterned, unfair, unjust and actionable, as opposed to random”

(Whitehead, 1992). Inequities in health involve distributive justice, with normative and ethical connotations. This term connotes judgment, includes assumptions about social justice, and expresses a moral commitment. Within an equity framework, responsibility for social conditions is placed on government institutions to address the needs of populations with varied access to social privileges (Alleyne, Casa, 7 Castillo-Salgado, 2000). Commitment to equity leads to transformative social policies that acknowledge and contest the power of elite policy makers.

In a more developed conceptualization of health within an inequity framework, an appropriate question would address, for example: Why is obesity increasing in rich countries? Answers to this question may include underlying social causes such as government subsidies to certain industries (like corn and cheap corn syrup production, which has contributed to the increase in obesity), and solutions may target government decisions regarding industry (such as evaluating health consequences of food products before subsidizing them and allowing them to enter the market). Inequity definitions lead to solutions at the macro level and point to the need to address government systems, distribution of power and economic resources. Beckfield and Krieger (2009) suggest that when studying inequity in health, researchers need to focus on the political processes that produce health inequities (these processes imply agency and accountability). They posit that the root of health inequities is social disadvantage caused by power differences resulting in inequitable distribution of resources. Beckfield and Krieger state: “power, after all, is at the heart of the matter” (Ibid, p. 18).

In sum, the definitions of the terms disparity, inequality, and inequity imply corresponding research questions, study designs and methods, analyses, interpretations, and implications for policies, as well as interventions affecting health. In the United States since the late 1990's, the discourse on health uses these terms interchangeably, and I would add carelessly, with predictable results. Vague definitions and understandings lead to inadequate solutions, costly in terms of human suffering, because they sidestep issues of power and injustice, agency and accountability (Krieger, 2008). Definitions in turn guide questions. An inequity framework aids in asking different questions that call attention to power (to make decisions about health), agency and accountability such as: How do policies that prioritize private gain and accumulation of wealth over human need affect health? How do political decisions that privilege a small elite affect health policies? Who makes those decisions? Whose interests are served?

Race, Ethnicity and Class

Race. The Census Bureau in 2000, using 1990 census data, based its definition of race on self-identification:

> [The concept of race] does not denote any clear-cut scientific definition of biological stock. The data for race represent self-classification by people according to the race with which they most closely identify. It is recognized that the categories of the race item, include both racial and national origin or socio-cultural groups" (United States Census Bureau, 2002).

As seen in the above definition, official government documents defined and measured race as an individual characteristic, not as a category based on social structure that "continues to signify difference and structural inequality" (Omi and Winant, p. 57). It should be noted that in 1997 the Census Bureau allowed individuals to report more than one race for the first time.

Omi and Winant state:

> Race is a concept which signifies and symbolizes sociopolitical conflicts and interests in reference to different types of human bodies. Although the concept of race appeals to biologically based human characteristics (so called "phenotypes"), selection of these particular human features for purposes of racial signification is always and necessarily a social and historical process (Omi and Winant, 1994).

The above statement succinctly expresses the contingency of race.

I base my own definition of race on sociological analysis, which is explained in the American Sociological Association's statement developed to underscore the importance of collecting and analyzing data for social scientific research (American Sociological Association, 2005). I see race as a multi-level social construct that changes over time, and structures social hierarchies that place groups and individuals in unequal and inequitable positions that affect their health and well-being.

Most health researchers do not define race or talk about how they measure it, although they widely use it, often as a proxy for class and other social conditions. Williams and Collins (2002) state:

> Race is a proxy for specific historical experiences and a powerful marker of current social and economic conditions that determine exposure to

> pathogenic factors. Advances in our understanding of the role of race in health are contingent on efforts to directly assess the critical aspects of race that are implicated in health outcomes (Williams and Collins, p. 411).

In Williams and Collins we find reference to social conditions that determine health, which I consider fundamental in studying structural conditions that result in health inequalities and inequities.

Ethnicity. In 2000, the Census Bureau, in accordance with the Office of Management, defined ethnicity as:

> The heritage, nationality group, lineage, or country of birth of the person or the person 's parents or ancestors before their arrival in the United States. People who identify their origin as Spanish, Hispanic, or Latino may be of any race.

As seen in the above, the Census Bureau based ethnicity on self-identification related to ancestry and country of origin, different from race, and considered it a separate concept from Hispanic origin. This is a definition at the individual level.

My own definition of ethnicity adds to the Census definition. I consider ethnicity, like race, a social construct that places different groups of people in unequal positions in society based on their ancestry and contingent on the historical context. For example, at this time groups such as Latinos from Mexico or refugees from the Middle East constitute disadvantaged ethnic populations targeted for discrimination and systemic and individual discrimination. Ethnicity, therefore, is also a multi-level phenomenon that includes individual identification with a group and the connotations that society imposes on that classification.

Class. The United States defines class by income, and decides what income bracket defines lower, middle and upper class. The following quotation from the Census Bureau indicates income as household income, and the data reflect the numbers in 1995:

> The Census Bureau does not have an official definition of the "middle class," but it does derive several measures related to the distribution of income and income inequality… Generally, the long-term trend has been toward increasing income inequality. Since 1969, the share of aggregate household income controlled by the lowest income quintile has decreased from 4.1 percent to 3.6 percent in 1997, while the share to the highest quintile increased from 43.0 percent to 49.4 percent. Most noticeably, the share of income controlled by the top 5 percent of households has increased from 16.6 percent to 21.7 percent. Over the same time period, the Gini index rose 17.4 percent to its 1997 level of .459. (US Census Bureau, 1995).

It is interesting to notice that the US government does not clearly define “middle class” a term used with great frequency in political discourse.

Sociological definitions of class, mostly derived from Marx and Weber[5], vary and there seems to be no consensus on what social class really means, other than it is related to income and the exchange relationship between capital production and distribution. I define class a social constructed category that denotes social position

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[5] Omi and Winant characterize Marx’s definition of class as “relationship to the means of production” and Weber’s as “relationship to the mode of distribution” and combine the two (Omi and Winant, 1998, p. 24).

based on income and wealth derived from distribution of capital; this distribution changes depending on a society's political and economic system/structure.

In summary, race, ethnicity and class are social constructions that help explain inequalities and inequities in health based on structural causes, and should be defined as multi-level (micro or individual; meso or institutional; and macro or governmental levels) variables. These categories, however, often go unexamined and unmeasured and change through time contingent upon socio-political and historic circumstances.

Conclusion

In this study I propose that government systems, as a macro level determinant of health, need to be acknowledged, researched and addressed when studying health determination and distribution. Macro level policies influence definitions of disparities, race, ethnicity and class at the individual level through government actions on taxation, safe and adequate housing, pollution control, occupational safety standards, availability of healthy food and living wages, etc. Such policies and actions contribute to unequal distribution of resources and of health outcomes. Addressing inequity falls within the purview of government and organizations rather than on individuals and/or medical services alone. Ideological differences that privilege disparity, equality or equity have a long history based on different frameworks used to explain health and illness. Divergent opinions through time seem to parallel institutional and governmental stances regarding the social determinants of health (Beckfield & Krieger, 2009). Unequal distributions of resources and health outcomes coincide with socioeconomic and racial inequities.

There is robust evidence of this relationship in many studies (Marmot, 2005; Navarro, 2009; Raphael, 2000; Wilkinson & Marmot, 1999, to name only a few). As Navarro states, “death and poor health are not randomly distributed in the world … this is a solvable problem, and we know how to do it” (Navarro, 2009, 424). In Chapter 2 of the dissertation I will trace the historical trajectory of such ideas as they coincide with political agendas and systems.

After centuries of accumulated knowledge and efforts to improve health conditions, we still live in a world where we seem to accept that “a girl born in Sweden will live 43 years longer than a girl living in Sierra Leone,” and, closer to home, “in East Baltimore, a black unemployed youth has a life span 32 years shorter than a white corporate lawyer” (Navarro, 2009, p. 424). Navarro also states, “the evidence that health and quality of life are socially determined is undeniably overwhelming” (Ibid). Evidence also indicates that social policies create inequities and that certain kinds of governments and political conditions increase health inequities. For example, in the Unites States during the 1980’s, life expectancy gains slowed markedly relative to other developed countries (Dow & Rehkopf, 2010). The 1980’s encompassed President Ronald Reagan’s market oriented policies and initiated an era of marked conservatism that, among other effects, weakened the safety net for vulnerable populations.

Understanding the construction of health disparities through discourse is important because it permeates health policies and health programs. As such, this construction has the potential either to eliminate disparities or to perpetuate them, thus contributing to increased health inequality and inequity. I hypothesize that one of the major reasons why *disparity* as a framework prevails in the United States has to do with its apolitical symbolism. By this I mean that a conceptualization based on a disparity definition does not have to address redistribution of material and political resources that play a pivotal role in determining health.

Chapter 2: Conceptualization of the Social Construction of Health Disparities

The “health disparities” discourse in the United States developed with a focus on race and ethnicity, individual responsibility and medical care. I aim to understand how this construction of health disparities happened, anchored on theories of social construction, hegemony and racial formation, and based on concepts of health as a social justice issue and a broad understanding of the socio-structural determinants of health.

Social Construction of Knowledge

The sociology of knowledge postulates that knowledge is socially constructed, meaning that knowledge depends largely on its context. Many sociologists and other scholars have contended with the social construction of knowledge (Berger & Luckmann, 1966; Gramsci, in Hoare & Smith, 1971; Mannheim, influenced by Marx, 1936). These scholars were interested in those with the power to construct knowledge; the ideas they favored; the historical circumstances and political environment in which they operated; and the dissemination of concepts to and acceptance by the masses. Thus, my study focuses on the agents responsible for the social construction of health, the influences guiding them, and the dissemination process that resulted in the dominant construction of “health disparities.” In the case of knowledge about health, I focus on the social construction of health as an individual phenomenon, nearly devoid of social context, that became hegemonic.

Hegemony

The ideas of the ruling class are in every epoch the ruling ideas, i.e. the class that is the ruling material force of society is at the same time its ruling intellectual force. The ruling class, which has the means of material production at its disposal, has control at the same time over the means of mental production, so that thereby, generally speaking, the ideas of those who lack the means of mental production are subject to it. The ruling ideas are nothing more than the ideal expression of the dominant material relationships, the dominant material relationships grasped as ideas" (Marx, 1845).

I rely first on the major sociological concept of hegemony within a Marxist frame: dominance of an economic (Marx & Engels, 1932) and political elite (Gramsci, 1971; Mills, 1959). Within the theme I analyze, hegemony works at different levels: 1) in terms of the apparent lack of analysis of the language used when describing health inequalities and inequities as disparities, and 2) as power of a small elite to inform not only the discourse but also the politics and policies that dictate health programs/interventions based on a market model (health as a profitable business) and health as individual responsibility.

The concept of hegemony or dominance of the ideas of the ruling class, whose members produce and distribute them, is intertwined with concepts of power and ideology and with the social construction of knowledge. One reason for the interconnection of these concepts lies in their having emanated from Marxist theory. While the genealogy and intellectual history of hegemony as a concept is not within the boundaries of this study, I rely on concept definitions from scholars who started with Marx's ideas and expanded upon them (Bourdieu, 2001; Gramsci, 1971; Mills, 1959).

Marx saw hegemony as a one sided process in which the bourgeoisie imposed its values and ideas on the rest of the population. Gramsci expanded the concept by adding that institutions in society coalesce with the ruling elite to socialize the population into its values and beliefs, making them appear as common sense, and as the natural order of things (Boggs, 1976). In other words, the ruling class or power elite has ideological control that serves to manufacture consent among the general population. In the end, a majority coalesces to support the status quo, and the ruling class maintains its power with the consent of the masses (Gramsci, 1971).

As long as power is concentrated on the top of the hierarchy, the absence of a commitment to equality and equity disproportionately and negatively affects health outcomes for people of color, for the poor, and for other groups that do not have access to power. In a society stratified by race as we have in the United States, people of color suffer the most from inequalities and inequities in health. To analyze the social construction of health inequalities and inequities then is necessary to understand racial dynamics, and to do so I use the concept of racial formation in my analysis.

Racial Formation

Omi and Winant (1994) propose a constructionist explanation of race. They define racial formation as “the sociohistorical process by which racial categories are created, inhibited, transformed, and destroyed” (Omi & Winant, 1994, p. 55). Their theory proceeds in two steps. In the first step, they argue that “racial formation is a process of historically situated projects in which human bodies and social structures are represented and organized" (Ibid, p.55). In the second step, they "link racial formation to the evolution of hegemony, the way in which society is organized and ruled" (Ibid, p.55). They see race as a fundamental organizing principle of social relationships. It is a process where social, political and economic forces determine racial categories and infuse them with racial meanings. Racial meanings extend from the micro level of relationships and formation of individual identities to the collective, macro level where economic and political structures are formed. In racial formation theory, the micro and macro levels, although analytically distinct, are linked in lived experience, politics and culture.

Omi and Winant use the concept of "racial projects" as a way to explain how society reproduces structures that maintain domination. "A racial project is simultaneously an interpretation, representation, or explanation of racial dynamics, and an effort to reorganize and redistribute resources along particular racial lines" (Ibid, p. 56).

The first racial formation project, according to Omi and Winant, happened with the conquest of the Americas that constructed civilization as the rise of Europe and the subjugation of the rest of the world. That event still defines racial politics. Omi and Winant argue, "Race is a political phenomenon" (Ibid, p.65). Racial projects maintain race as a category of oppression and domination. I posit that one major consequence of this oppression is health inequity and the failure of society and the state to recognize the deep roots of health inequities.

Because a Marxist perspective is based on class analysis and the racial formation perspective is based on race analysis and each subsumes the other, there is a tension in my analysis. I will address this tension as I study the documents and interviews to find the underlying concepts that lead to the dichotomy of race and class.

In addition to the above theories, two strands of thought influence my understanding of the sociology of health and guide this dissertation. The first is based on a conception of health as a social justice issue and as a right, as opposed to a commodity distributed according to individuals' ability to pay. This conception requires an equity framework. The second is anchored in the body of knowledge referred to as the social/structural determinants of health including the political economy as a major determinant, as consistently pursued by the WHO's Commission on the Social Determinants of Health (2008).

Health as a Right or Social Justice Issue, Not a Commodity

Several scholars in sociology, public health and other fields have advanced a social justice perspective on health. Parsons (1965) posited that since health is paramount to the function and equilibrium of society, it is society's responsibility, and incompatible with a business/market model. Rawls, in "Theory of Justice" (1971), conceived of justice as fairness based on cooperation where "[t]he distribution of wealth and income, and the hierarchies of authority, must be consistent with both the liberties of equal citizenship and equality of opportunity" (Rawls, 1971, 61). Even though he did not address health, other scholars use Rawls' theory and principles of distributive justice extensively to base their own theories of health and social justice (Peter, 2001). An important concept of Rawls places principles of justice not on individuals, but on public rules and the substantive structure of institutions of society.

Daniels (1985) posited that health is essential for an individual's pursuit of liberty and for species functioning and that, since most decisions that affect health are made at the macro-level, it falls within the state's responsibility to address inequalities in health, and that these decisions should be framed within moral principles of justice. Waitzkin (2001) further addressed the lack of moral commitment in the United States to consider health as a right, which prevents developing a system of universal health.

In summary, from conceptions of health as paramount in the functioning of individuals and society, I see health as a right, as a social justice issue, and health care as incompatible with the business model. Therefore, the sociology of health should concern itself with issues of morality and justice, and of how society, through the state, fulfills its responsibility to assure the health of the population. Thus, my research asks what questions we privilege, which do we neglect to ask, and why. Questions such as these will help bridge the gap between knowledge and the power to apply it to policy and politics by getting at the roots of the problem of health inequities and the undergirding system that is responsible for them, and that is based on market justice (Beauchamp, 1976), as derived from a market-based economy.

The Social/Structural Determinants of Health

There exists a long history of recognition that health is affected by the conditions under which people live. These conditions are usually determined by governance structures based on prevailing political economies. For example, in 5th Century BC Hippocrates stated that a "contributory cause" to health was people's ability to self rule and to labor on their own behalf (Lloyd, 1983) and that “those with power, property, freedom, and leisure had better health than ‘‘the mass of people who are obliged to work,’’ who ‘‘drink and eat what they happen to get’’ and so ‘‘cannot, neglecting all, take care of their health’’(Sigerist, 1961). This example illustrates that the idea that political environments affect the distribution of health has an ancient tradition. However, in contemporary sociology, with few exceptions (Beckfield & Krieger, 2009; Navarro, 1993; Waitzkin, 2001) the history of social determinants is not acknowledged and there appears to be a paucity of research on contemporary “political contextual analysis” of how “political context matters for health at various points in the distribution of social inequity” (Beckfield & Krieger, 2009, p. 168).

A paper written by Link and Phelan (1995) posited that there are fundamental causes of disease that determine health and illness: access to power, money, knowledge, prestige, and beneficial social connections. These are, in turn, determined by socio economic status (SES). Individuals with better education and income use their SES to access better health. This theory contradicted prevalent beliefs about health as biologically determined, and as a matter of individual life-style choices. Living conditions can constrict or encourage certain choices. And, if the causes of those living conditions are addressed, policies and interventions to improve health and diminish health inequalities are more effective because they are not geared towards changes in individual behavior but, instead, towards changes in society.

The theory of fundamental causes calls for different and more effective interventions, not at the individual, but at the societal level. This means that to address inequalities in health, policies needs to address housing, food access, taxes, minimum wage, and work conditions, among others. I should mention that Link and Phelan's theory (1995) is considered pivotal and new. It is worth noting that Link and Phelan did not acknowledge the well-known and long history of social determinants. It is also worth mentioning that these authors only peripherally addressed the influence of race (and gender) in a footnote in their 1995 paper.

Marmot and Wilkinson (2006) compiled solid extant research with evidence about multiple social causes of illness. They posited that beyond poverty, there was social meaning attached to living conditions that affected health and illness. Their more comprehensive list of social determinants of health included experiences of early life, work, social support, stress, the gradient of health, food access, employment, transportation, support, and education, among others. This list contained more specific determinants that needed to be addressed by the state if the health of the population were to improve.

A number of researchers added a socio political and economic dimension to previous theories (Beckfield & Krieger, 2009; Krieger, 2008; Navarro, 2004; Waitzkin, 2001, among others). They conducted studies, compiled evidence, recalled forgotten history, and argued that the theories of fundamental causes of disease, particularly when based on socio economic status, amounted to policies without politics. They interpreted the emphasis on status as a way of not addressing class, and inferred that it was a political decision to use socio economic status indicators (SES) instead because it was an approach that did not threaten the dominant classes, therefore a more acceptable and palatable approach. Navarro, when giving an address in response to the World Health Organization's report in 2009, stated that health is affected by the ways in which people are born, live, work and grow, and that the real causes of the causes go beyond socioeconomic status (SES). He emphasized the role of agency in health inequalities and the importance of addressing the realities of concentrated political-economic power if real changes in health inequality were to occur. For these scholars, health is a social justice issue that requires interventions at the macro level. Navarro has often said that we know what to do to end inequalities that would improve the health of the population across the world, referring to a fair economic distribution that requires transformation of society.

An incipient and more recent body of literature is looking at macro level processes that contribute to shape health and illness such as globalization, trade policies, deregulation and other political and economic strategies (e.g. Labonte & Schrecker, 2007; Blouin, Chopra, & van der Hoeven, 2009; Jasso-Aguilar, Waitzkin, & Landwehr, 2008). These variables have not received much attention in the literature of health determination in spite of their pivotal role in health distribution. Studying health and the pursuit of health equity from a sociological perspective requires a social, political, and economic conscience that looks at comprehensive determinants of health and addresses research questions accordingly (Krieger, 2006). The present study investigates who privileges what questions, which questions are not asked, and what interests are or are not represented. Answering these questions will help bridge the gap between what we know about health and the power to apply it to policy and politics, and has the potential of uncovering the roots of the problem of health inequalities and inequities and the undergirding system that is responsible for them, namely the present capitalist economy.

A conceptual framework built on equity has increased my passion for social justice, and solidified my commitment to study "up," meaning looking at the systems and agents that socially construct health and illness at the macro level, and their effects on the population. The ultimate purpose of this study rests in understanding the mechanisms that lead to construction of hegemonic (dominant, ruling) concepts that concentrate power in a small privileged elite, to the detriment of the majority. Thus, two main arguments guide this study.

First, the use of the term "health disparity" was implemented because it involves much more than a semantic change. It has affected and continues to influence how health research is conducted – the questions investigated, the methods used, the data collected, and the interpretation of the research. In turn, and more importantly, policies that result from the conceptual change from inequity to disparity prevent social changes and negatively affect the health of the population, particularly underrepresented populations such as Latinos, Native Americans, African Americans, and the poor and disenfranchised. For example, one major change includes the myriad policies and programs that concentrate on addressing individual life-style choices as opposed to structural, systemic health determinants. The '"health disparity" construction absolves the wealthier classes from any responsibility to address greater inequities in society.

The second argument, based on the concept of hegemony and the social construction of knowledge, asserts that the disparity construction was carefully engineered to meet the demands of a market conception of health and health care to benefit the most advantaged members of society. This study aims to find out how the political decision to change the language happened, the interests behind it, and how the language change has guided concepts in research, policy and practice regarding the health of the population in a direction congruent with and supportive of the political economy, with disregard for equity and negative effects on disenfranchised populations.

The International Discourse

While in the United States, in the late 1990's and 2000s, the discourse about health seemed focused on "disparities," internationally the focus on "health equity" dominated. This phenomenon is exemplified in the discussion that ensued after the WHO published the World Report 2000. There were numerous critiques of this report because it "removed equity" defined in this context as "… an ethical value that may be operationally defined as striving to reduce systematic disparities in health between more and less advantaged social groups within and between countries" (Braveman et al., 2001, p.679). Unlike previous WHO reports, the World Health Report 2000 did not measure social or health inequalities within countries. It did not provide information about what accounts for ill health distribution, or guidelines on how to address it (Braveman et al., 2001); and it placed medical services and the amount a country spends on medical care as more important than social, economic and political interventions (Navarro, 2000). The controversy and array of critiques at the international level demonstrates that the equity concept in health was not only recognized but also highly valued in the international community.

In the meantime the same issues that were highly criticized at the international level seemed to become the principles guiding policy in the United States. For example, official government reports such as Healthy People 2000 and 2010 did not account for causes of health inequities (which were defined as “disparities”), These two documents narrowed the definition of health to medical care, as opposed to considering health in the broader context of wellbeing.

The WHO created the Commission on the Social Determinants of Health (CSDH or the Commission) at the 2004 World Health Assembly as a key component of its equity agenda. The Commission’s Director, Sir Michael Marmot, clearly stated, “If the determinants of health are social, so must be the remedies” (Marmot, 2005). The Commission has continued its role as the voice that represents principles of health equity and social justice because it believes that the evidence supports the premise that reduction of disease can only be attained by taking the social determinants of health adequately into account (Lee, 2003). The Commission publishes periodic reports that demonstrate its commitment to reducing health inequities and makes the connections between structural determinants of health as including the social, economic and political context that is responsible for health inequities.[6]

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[6] For example “A Conceptual Framework for action on the social determinants of health” (2010).

Conclusion

The persistent problem of inequalities and inequities in health in the United States became a “health disparities” problem starting in the late 1990s. The “disparities” discourse focused on differences in health outcomes between Whites and racial and ethnic minorities; individual responsibility for life-style choices; and medical care, not overall wellbeing. I adapt theories of hegemony and class formation and extend them to analyze how the decontextualized construction of health disparities happened.

In the next chapter, I present the methods I used to analyze critically the discourse on health disparities that dominated politics, policy and academia until recently.

Chapter 3: Research Design and Methods

To answer the research question for this study: “How was the social construction of health disparities among racial, ethnic and other disadvantaged populations accomplished and implemented?” I use the following approach:

Qualitative analysis of selected public documents

Qualitative analysis of key informant interviews, and

Limited quantitative content analysis (count of the terms “health disparities,” “inequalities,” and “inequities” in the documents and in books about health).

Data Collection

Document selection. I reviewed archival literature using Thomas.gov, a website that provides legislative information, and conducted research at the Library of Congress in Washington, DC. I selected official documents developed and published by federal government agencies and/or by independent agencies commissioned by Congress between 1970 and 2010, with a particular focus on the Clinton administration. The documents I chose represent the theoretical and political foundation used in the social construction of health disparities that served as important guides for health policy and practice in the United States, and exemplify the thinking of the time under consideration in my study regarding health policy and politics. I targeted reports that had the most impact on policy because of their contents and reach.

List of documents (all documents are available online):

a) Minority Health and Health Disparities Research and Education Act of 2000. (Public Law 106-525, 106th Congress)

b) "Healthy People" reports from 1990 (written in 1979), 2000 (written in 1998), 2010 (written in 2002), and 2020 (written in 2010). "Healthy People" reports outline health policy goals reflecting political trends that directly influence policy and program funding for the years following their publication. These reports are published every 10 years by the US Department of Health and Human Services with input from a variety of stakeholders. The "Healthy People" reports represent consensus among a fairly large number of actors from different federal agencies, states health departments, as well as comment from researchers and the public. These reports set the strategy that guides national health initiatives. I chose years 1990 (written in 1979), 2000 (written in 1990), 2010 (written in 1998-2000), and 2020 (written in 2008-10 in order to assess whether there was a change in language and to deduce critically whether and how the language shift was associated with changes in health goals, measurements, and recommendations.

c) Key reports by the Institute of Medicine (2002), and by the Agency for Healthcare Research and Quality (U.S. DHHS, 2003). These reports elucidate the process of scientific research that ensued from the political context.

d) World Health Report 2000 that, even though published by the World Health Organization, was influenced by United States policy.

My analysis of the reports is mostly based on information in the summaries. However, since some of the summaries are not as comprehensive as others, I read and coded all the reports in full and, if an area was not clear in the summary I referred to the full section in the report to clarify it. An analysis based on summaries alone would have missed important statements.

I originally planned to examine records of preliminary hearings that did not get included in the official versions of the reports I analyzed. However, upon discussion with the committee, we decided not to include this piece of research in order to meet deadlines and finish the study in time.

Table 3.1 shows the list of documents analyzed, and Table 3.2 shows the "Healthy People Reports" goals and priorities.

Table 3.1. *List of Reports Analyzed.*

Report	Year published	Total # of pages	Executive Summary # of pages	Title	Authors
Public Law 106-25	2000	17	N/A	Minority Health and Health Disparities Research and Education Act	106th Congress (President Clinton). Presented by Sen. Edward Kennedy (D-MA)
Healthy People 1990	1979	262	13	The Surgeon General's Report on Health Promotion and Disease Prevention	Julius B. Richmond, DHEW*
Healthy People 2000	1998	845	29	National Health promotion and Disease Prevention Objectives	Louis W. Sullivan, Secretary DHHS**& James O. Mason, Assistant Secretary for Health
Healthy People 2010 Vol. I	2002	242	47	Understanding and Improving Health	Donna E.Shalala Sec. DHHS** David Satcher, Asst. Sec. Health & Surgeon General

Table 3.1 Continued

Report	Year published	Total # of pages	Executive Summary # of pages	Title	Authors
Healthy People 2010 Vol. II	2000	319	10	Objectives for Improving Health (Focus areas 1-14)	Donna E. Shalala, Sec. DHHS** David Satcher, Asst. Sec. Health & Surgeon General
Healthy People 2020***				Improving the Health of the Nation's population and Achieving Health Equity	Kathleen Sebelius, Sec. DHHS & Dr. Regina Benjamin, Surgeon General
World Health Report 2000 (WHO)	2000	265	21	Health Systems: Improving Performance (Focus areas 15-28)	Julio Frenk and Christopher Murray (Responsible for conceptual framework)
Institute of Medicine (IOM) Report	2003	414	27	Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare	Brian Smedley, Adrienne Stith, Alan Nelson Eds.
Agency for Health Care Research and Quality (AHRQ)	2002	227	11	National Healthcare Disparities Report	DHHS Secretary Tommy Thomson

* DHEW: Department of Health, Education and Welfare, Washington, D. C.
** DHHS: Department of Health and Human Services
*** Phase I Report: Recommendations for the framework and format of Healthy People 2020. The full 2020 report is in progress.
NOTE: The years 1990, 2000, 2010, and 2020 in the titles of Healthy People Reports represent the end of the decade, when the goals should be attained, not the year in which they were developed. For example, Healthy People 1990 was written in 1979, Healthy People 2000 was written in 1990, and so on.

Table 3.2. ***"Healthy People" Reports: Goals and Priority Areas.***

Report	Goals	Priority Areas
Healthy People 1990 The Surgeon General's Report on Health Promotion and Disease Prevention	Reduce mortality among infants Reduce mortality among children Reduce mortality among adolescents Reduce mortality among young adults Increase independence among older adults	15 priority areas and 226 measurable objectives
Healthy people 2000 National Health Promotion and Disease Prevention Objectives	Increase years of healthy life for Americans Reduce disparities in health among Americans Achieve access to preventive health services for Americans	22 priority areas and 319 objectives
Healthy People 2010 Objectives for Improving Health	Increase the quality and years of healthy life Eliminate health disparities	28 priority areas 955 measurable objectives & sub objectives 10 leading health indicators
Healthy People 2020	Attain high quality, longer lives free of preventable disease Achieve health equity, eliminate disparities Create social and physical environments that promote good health Promote quality of life, healthy development, and healthy behaviors across life stages	42 topic areas 24 objectives

Source: Jackson Allen & Meadows-Oliver, 2011
Bibliographical note: Jackson Allen P. & Meadows-Oliver M (2011). Healthy People 2020: Our Guide to the Next Decade's Health Priorities. Yale University School of Nursing.

The above table illustrates the different goals in the Healthy People Reports and the increase in the number of priorities.

Key informant selection. I selected the key informants through a purposeful sampling method (Maxwell, 2005, 87-88; Light, Singer, & Willet, 1990, p.53). Purposeful selection is "a strategy in which particular settings, persons, or activities are selected deliberately in order to provide information that can't be gotten as well from other choices" (Maxwell, 2005, pg. 88). Most of the key informants were in Washington D.C. at the time when the social construction of disparities was taking place. Others participated in the discourse from their respective settings (universities and/or agencies).

I identified and selected key informants among those who were at the center of the discourse on *health disparities* in the late 1990's and early 2000's linguistic and conceptual shift in Washington D.C. at the time it occurred. I looked at the lists of persons who were involved in the development of the reports, discussed the identification and selection of key informants with individuals who worked for the Clinton administration and others who, because of their academic work, were familiar with the individuals who wrote the reports I included for analysis. Some key informants gave me names of other possible interviewees.

Using all the information above, I compiled a list of possible key informants, studied their vitas and based on their participation in policy in the late 1990's, selected about 30 names. I chose these individuals because they comprised a mix of policy-makers at the highest level of federal government, staffers and Washington insiders, academics with broad experience in policy, and from agencies involved in "health disparities" discourse. I also wanted to have Black, White, Latino and American Indians in the group, since I was analyzing issues of race and ethnicity. Of the 30 informants selected 18 responded affirmatively, 3 stated they did not believe they were appropriate for my study, 3 had schedules that did not permit interviews during my data collection time line, and the other 6 did not respond in spite of my repeated letters and/or phone calls.

I stopped interviewing when I reached saturation -- when key informants began to repeat what had been previously stated, and when I decided that interviewing more people would not add new information or more depth to the study[7] – (Cresswell, 2009; Glaser & Strauss, 1967; Guest, Bunce, & Johnson, 2006). In fact, saturation was reached after 14 interviews.

The preliminary interview sample appears in Appendix 1 on this document (p.187). I piloted the questions with one individual before completing the final version. The key informants were all elites, defined in this study as highly placed academics/researchers, and/or policy-makers, and/or administrators. Table 3.3 illustrates the demographics of the key informants.

Table 3.3. *Demographics of key informants.*

Key Informant	Sex	Role	Degree
KI 001	F	Academic/Policy	MD PhD
KI 002	M	Academic/Policy	PhD
KI 003	M	Policy/Administration	PhD
KI 004	M	Academic/Policy	MD PhD
KI 005	M	Academic/Administration	PhD
KI 006	F	Academic/Policy/Administration	PhD
KI 007	M	Academic/Policy/Administration	PhD
KI 008	F	Academic/Administration	PhD

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[7] Research on qualitative saturation has not evolved much since Glasser & Strauss (1967) and Cresswell (2009). However, the Guest, Bounce and Johnson found that when "the aim is to understand common perceptions and experiences among a group of relatively homogeneous individuals, 12 interviews should suffice" to reach saturation. In fact, this was the case in my study.

Table 3.3 Continued

Key Informant	Sex	Role	Degree
KI 009	F	Academic/Administration	PhD
KI 010	M	Academic/Policy/Administration	MD PhD
KI 011	F	Academic/Policy	PhD
KI 012	F	Policy/Administration	MD
KI 013	F	Policy/Administration	MD PhD
KI 014	F	Policy/Administration	PhD

Developed by author based on information on CV's –available online.

The table shows that I interviewed 8 females and 6 males. All 14 hold PhD's and 4 of the 10 also hold MD's, and hold - currently and have held in the past – important positions in academic and/or political and/or administrative roles. Although not included in the table (to avoid any possibility of identification) the group included 9 White, 2 Black and 3 Latino respondents.

Key informant interviews. I conducted semi-structured, open-ended, depth-probing interviews with key informants following guidelines by Glesne (2011). According to Glesne (2011, 134) semi-structured interviews contain "specified questions you know you want to ask:" open questions arise in the course of the interview, and "you [the interviewer] are prepared to follow unexpected leads that arise in the course of your interviewing"]; and depth-probing involves pursu[ing] all points of interest with variant expressions that mean "tell me more" and "explain." This type of interviewing captures the full complexity of the issues and of the accounts by the interviewees. Through the interviews I aimed to gain an understanding, in its fullest complexity, of the phenomena under analysis and respondents' experiences within their roles as either policy makers, analysts, and/or or writers.

I developed a set of questions I provided to the key informants ahead of time to start the conversation and followed leads to depth-probe. Specifically, I looked for ways in which respondents contributed to construction of the discourse about health disparities, or how they experienced the construction happening. I conducted the interviews by telephone. With authorization from the key informants I took notes, digitally recorded the interviews, and had them professionally transcribed (except for one who did not give me permission to either record or transcribe). All the informants opted for anonymity with some insisting that I guarantee they would not be identifiable and that I would destroy the recordings as soon as I transcribed them.

Interviewing the key informants posed some challenges since all of them were very busy, most still working in full-time positions with busy travel schedules, and had staff that screened their contacts. I needed to identify these gatekeepers in order to schedule interviews. I sent information packages to each of the identified individuals with a letter of introduction, the interview questions, and the IRB approved consent form[8]. I followed up with an e-mail message and a phone call if

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[8] I only received two responses after the first 10 letters went out, and did not succeed much more with phone calls or e-mails. When I sent the letters on stationary from the Robert Wood Johnson Foundation Center for Health Policy the response was greater.

necessary. In some instances I made up to 3 or 4 phone calls. Once the interviews were scheduled, all of the informants were on time.

While some key Informants seemed reserved at the beginning, all shared without difficulty once the ice was broken. While a few interviewees talked with me for an hour or even longer, most were only available for 30 minutes. This divergence of time required flexibility in how I conducted the interviews. Most interviewees had read the questions ahead of time and were prepared to talk and address the main points without much prompting on my part. Depending on their role during the Clinton administration not all the questions had the same relevance to all of the informants. I often chose to probe deeply in some areas at the expense of not getting to all the questions, since my goal was to understand how the construction of health disparities happened. Since I recorded 13 of the interviews and had them transcribed, and took notes on the last one, I did not lose any of the information, even though it was given in mostly a conversational style.

Data Analysis

I conducted qualitative analysis of the selected public documents and interviews to ascertain whether and how the conceptual and linguistic use of the term “disparity” informed the policies and recommendations that ensued. Specifically, I looked at definitions of disparities; the underlying, dominant value placed on “life-style” and “personal responsibility;” recommendations to improve health; and whether or not the discourse was about health care or health in the broader sense of wellbeing, not just the absence of disease.

Critical Discourse Analysis (CDA) is an analytical approach that guides the researcher to understand how dominant ideologies and power relationships, expressed in discourse, mediate and perpetuate social problems. CDA is designed to clarify the connections between the use of language and the exercise of power, which are not always clear (Thompson, 2004). The techniques of CDA guided me to discern the assumptions and underlying values expressed in the texts, and the interests behind the language and policy expressed in the interviews and documents.

Official texts, an important part of the political discourse, contain evidence of how power works. According to Fairclough, “texts constitute a major source of evidence for grounding claims about social structures, relations, and processes” (1995:209). More importantly, discourse can be used to make unbalanced power relations appear normal and can hide discrimination and inequities and larger systemic issues like race, class, gender and religion, among others (Fairclough, 1995, 2000; Huckin, 1997; McGregor, 2003; Thompson, 2004; van Dijk, 1999). By critically analyzing the discourse in official documents, I aimed to find whether and how the concept of “health disparities” was constructed.

Critical Discourse Analysis techniques helped me capture the underlying power dynamics implied in the texts and the interviews. In preliminary analysis of the documents I found that I could read several pages without finding much to code or analyze. Frustrated, I was ready to give up CDA when I realized that the absence of values, and what I was “not” finding was, in fact, important, and signaled what might have been an effort to present *health disparities* as a phenomenon devoid of causes or even associations with larger societal issues and structures. By not addressing issues such as income and racial inequality, and other structures of society that have differential health effects on ethnic, racial, ethnic and disadvantaged populations when compared to whites, the texts spoke volumes.

The analysis process included iterative readings to code and interpret as recommended and used widely by sociologists and researchers in other fields (Fairclough, 1995; Gibbs, 2007, 48; McGregor, 2003; van Dijk, 1993, 1999 & 2003; Waitzkin, Yaeger, & Santos, 2011, and Waitzkin, 2000). This approach, designed to "analyze the complex relationships between dominance and discourse" (van Dijk, 1993, 252), guided me to discern whether and how hegemony and racial formation manifested in the documents and the interview material, and how they influenced the construction of health disparities.

Guided by the conceptual framework I developed my coding scheme through a combination of previously decided upon categories, and new categories that appeared during the coding process. I organized individual codes under subthemes and then synthesized as major themes present throughout the documents. Glasser and Strauss (2009) describe coding as the process of associating certain words with selections of data to organize data. I looked for terms such as "disparities," "life-style changes," "individual responsibility," and "lifestyle changes" among others, as a way of linking data and ideas into patterns and relational categories (Glesne, 2011, 195). Besides finding relationships between codes, topics and general themes, abstracting (Morse & Richards, 2002) and interpreting what was in the discourse, I used techniques of Critical Discourse Analysis to find out what was emphasized or de-emphasized, how, what was missing or absent, what was in the forefront, and what language structures (propositional, argumentative, etc.) were used.

I used Atlas ti 7.0 as a tool to help organize and code the data I collected. I chose this software program based on descriptions of the different software systems and on the experiences of other researchers with different programs.

Specifically, my analysis helped discern whether and how hegemony and racial formation manifested themselves through the written and oral data in the process of socially constructing health disparities. Table 3.4 illustrates the steps of CDA. There are several ways to use CDA. I found Huckin's steps to be concise and applicable to my study. I followed the steps and kept the concepts in mind when coding and analyzing the textual and interview data.

Table 3.4. *Critical Discourse Analysis Steps.*

Steps	Description/ What to look for
Frame	Look at text as a whole. Find keywords that place concepts in fore/background. What was left out or ignored?
Missing voices	"What could have been said that wasn't and why not?" Find voices used to convey legitimacy, voices left out
Topicalization	Look at sentences, phrases, and words for agency: to create a perception. Who is powerful/powerless? Why?
Weight/Power	What is taken for granted by the speaker? How does an agent with more weight convey power?
Misleads	What is used to deny any intention to mislead? What are the double meanings?
Persuasion	What word connotations are assigned on basis of participant's cultural knowledge? What word connotations turn uncritical minds in a desired direction?

Based on Huckin, 1997

Guided by the steps in the table above, I was able to focus on the role of language in the construction of health disparities.

Table 3.5 illustrates samples of codes, general themes, and concepts based on the conceptual framework.

Table 3.5. *Sample Codes Themes Concepts for Analysis of Data*[9]

Topics/codes	Themes	Concepts
Personal choices	Individual responsibility prioritized as a determinant of illness	Hegemonic belief
Life style choices	Life style choices practices such as exercise are recommended without contextual awareness	Hegemonic belief
Genetic variations attached to race and ethnicity	Race as biology responsible for health 'disparities'	Racial formation
Cultural differences	Racial or ethnic differences Responsible for negative health outcomes (as opposed to poor living conditions due to societal causes)	Racial formation
Health disparities	Elimination of health disparities defined as health differences between blacks and whites	Hegemonic belief
Changing demographics	Used as code for increasing diversity of the population	Racial formation
Leading health indicators	Prioritization of physical inactivity, overweight and obesity, tobacco use, etc.	Hegemonic belief
Individual solutions	Education programs to change eating and exercise habits	Hegemonic belief

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[9] This table shows some of the codes, themes and meta-codes or super codes I developed in the analysis as related to the conceptual framework of the study.

I converted emerging topics from the text into main themes and then discerned how they fit into the conceptual framework of my study, as the table shows. I did not code for inequality and inequity because, as explained in the content analysis, these terms were not used in the documents.

After reading the texts several times (reports and transcribed interviews) and pulling emerging common themes, I analyzed the findings. The concepts of hegemony and racial formation served to group the themes together and to find their meaning within the framework.

The Institutional Review Board (IRB) approved my study in January of 2012 and the continuation of the study in January of 2013.

Limited content analysis. In my prospectus I proposed a limited content analysis to illustrate – with numbers and images – the dramatic increase of use of the word "disparities," in comparison with the words "inequality" and "equity" and their derivatives before the 1990's and after. For example, to capture "disparity" and "disparities," I looked for "disparit." Similarly, I looked for "equalit" and "equit" using Microsoft word (word count).

I conducted the counts of the terms above using two sets of data. First I counted the words in the Healthy People Reports, calculated proportions, and compared the results to see the change of the discourse in the years between 1979 and 2010. Second, I added the other reports I analyzed to the first sample to see if the use of "disparity" had also spread to other official government documents.

For this analysis, I followed guidelines established by Weber (1990, pp. 70-79) for measurement (e.g. proportionate count of terms taking into account the length of each document); inferring meaning based on the numbers; and interpreting meaning as suggested by the conceptual/theoretical framework. I also used some of the methods used by Morning (2008); mainly, I performed the content analysis on the documents I used for the analysis, since I was familiar with them, to make sure that the words I counted were used and meant as I had envisioned.

In addition, I looked at the use of the same words (disparity, equality, equity) and their derivatives in the general discourse about health. For this analysis I used Google N-Gram Viewer[10]. N-Gram Viewer is a program in Google where "you enter phrases into the Google Books Ngram Viewer, [and] it displays a graph showing how those phrases have occurred in a corpus of books" (Google, N-gram viewer, 2012). I entered the following phrases: Health inequality, health inequalities, health inequity, health inequities, health disparity and health disparities from 1970 to 2008 (the last year available in N-Gram.

I understand that the N-Gram Viewer may not be "a scientific tool" vetted by sociology. However, I present it here to illustrate the interesting upsurge of the "health disparities" discourse that started in the late 1990's. I present the results of the data analysis in the last section of Chapter 5.

The content analysis I conducted is very limited. Partly, I used it to give a graphic representation of the interesting change in discourse. However, for several reasons, it is only a rough estimate. First, not all the reports are written in the same format or using the same fonts or spacing. For example, the report written in 1979

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[10] For more information on N-Gram Viewer got to "http://books.google.com/ngrams/info"

appears to have been typed on a typewriter and digitized recently. Second, I was not able to perform a total word count of all the reports. Instead I had total pages. Therefore I calculated the number of times the words in question appeared per page in each of the documents. However, I used the same method of calculation in all the reports for consistency.

Chapter 4: Findings from Healthy People Reports

Introduction

To answer the research question in this study: How was the social construction of health disparities among racial, ethnic, and other disadvantaged populations accomplished and implemented? I begin by analyzing official government reports that are used in the United States to guide and set health policy for the nation, starting with the four Healthy People Reports (HPR's) published to date. I use critical discourse analysis techniques to look at how health policy was constructed from the late 1970's to early 2013, how health disparities were portrayed and what interventions were recommended to address them.

The first Healthy People Report (HPR), "Healthy People: The Surgeon General's Report On Health Promotion and Disease Prevention" was developed in 1979[11] during President Carter's administration. The report consists of objectives to guide health policy and action to improve health and quality of life for the following ten years, and it started a precedent for the four reports that followed. The U.S. Department of Health and Human Services (HHS) is charged with developing the reports with the help of key stakeholders in public health at national, state and local levels. The HHS also elicits input from the public, and is in charge of disseminating the HPR's broadly across the country. The reports build on each other based on final progress reviews performed during the ten years following their publication.

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[11] It should be noted that the year in each report's title signifies the end year for its goals. For example, Healthy People 1990 was written in 1979, HPR 2000 was written in 1990, HPR 2010 was written in 2000, and HPR 2020 was written in 2010.

Major Characteristics of Healthy People Reports

While the reports share many similarities in terms of content and form, they also diverge in significant ways. Since each report was originally developed under a particular administration, and the ideologies of their authors and political leaders may have affected the discourse in each document, as a point of reference I list the government officials, including the Nation's Presidents, who were ultimately responsible for the reports in Table 4.1.

Table 4.1. *Healthy People Reports in Context*

Report Title	1990 The Surgeon General's Report On Health Promotion and Disease Prevention	2000 Promoting Health Preventing Disease	2010 Understanding and Improving health	2020 Healthy People in Healthy Communities
Year Report Developed	1979	1990	2000	2010
US President	Jimmy Carter (1977-1981)	George H.W. Bush (1989-1993)	Bill Clinton (1993-2001)	Barack Obama (2009-2017)
Surgeon General	Julius B. Richmond	C. Everett Koop	David Satcher	Regina Benjamin
Secretary (or Assistant Secretary of HHS	Joseph A. Califano, Jr.	Louis W. Sullivan (Sec.) James O. Mason	Donna E. Shalala	Kathleen Sebelius

Source: Healthy People Reports

It is worth mentioning that the development of each report required monumental effort, each progressively involving more experts and more public comment. HPR 1990 (in 1979) involved a number of experts in health and health policy, about 12 agencies and feedback from over 100 individual contributors. It had 15 priority areas and 226 objectives. HPR 2000 (in 1990) had a consortium of over 10,000 agencies and individuals participating in its development. It contained 22 priority areas and 319 objectives. HPR 2010 involved a consortium of 350 national organizations, 250 state agencies, a variety of federal agencies, 3 national meetings and more than 11,000 comments. It contained 28 focus areas and 467 objectives. HPR 2020 built a public comment Website for comments by users, held six regional meetings across the country and meetings in Washington, D.C. with the full advisory committee.

Every state has a Healthy People coordinator, the reports are widely disseminated to state, local and tribal entities, and they are used as data sources for planning, setting priorities, grant applications, outreach and research across the nation (National Opinion Research Center, 2010). Table 4.2 illustrates the expansion of Healthy People Reports through the years.

Table 4.2. ***Expansion of the Healthy People Initiative Over Three Decades***

	HP 1990	**HP 2000**	**HP 2010**	**HP 2020**
# of categories	15 priority areas	22 priority areas	28 focus areas	42 Interventions, Determinants, and Outcomes
# of objectives	226	319	467	

Source: Healthy People 2020: Phase I Report, October 28, 2008.

HPR's are full of important underlying assumptions about the meaning of health, assumptions and/or rules about what can be talked about and what can only be implied in cautious ways, about how individuals and communities live and act and make choices, and about the conditions under which people in marginalized communities manage their health. I will look for and point to the underlying assumptions as part of the critical discourse analysis of the documents. Before I analyze the reports in detail, I present an overview of all the reports in Table 4.3, where I list the priority areas to illustrate similarities and differences in foci between the reports.

Table 4.3: *Healthy People Reports Priority Areas by Year*

Healthy People 1990 Priorities		
Preventive Health Services	Health Protection	Health promotion
1. High blood pressure control 2. Family planning 3. Pregnancy and infant health 4. Immunization 5. Sexually transmitted diseases	6.Toxic agent control 7. Occupational Safety and Health 8. Accident prevention and injury control 9. Fluoridation and dental health 10. Surveillance and control of infectious diseases	11. Smoking and health 12. Misuse of alcohol and drugs 13. Nutrition 14. Physical fitness and exercise 15. Control of stress and violent behavior
Healthy People 2000: Focus Areas		
Health Promotion	Health Protection	Preventive Services
1. Physical activity and fitness 2. Nutrition 3. Tobacco 4.Alcohol and other drugs 5. Family Planning 6. Mental health and mental disorders 7. Violent and abusive behavior 8. Educational and community-based programs	9. Unintentional injuries 10. Occupational safety and health 11. Environmental health 12. Food and drug safety 13. Oral health	14. Maternal and infant health 15. Heart disease and stroke 16. Cancer 17.Diabetes and chronic disabling conditions 18. HIV infection 19. Sexually transmitted diseases 20. Immunization and infectious diseases 21. Clinical preventive services 22.Surveillance and Data Systems
Healthy People 2010: Focus Areas		
1. Access to quality health services 2. Arthritis, osteoporosis, and chronic back conditions 3. Cancer 4. Chronic kidney disease 5. Diabetes 6. Disability and secondary conditions 7. Educational and community-based programs 8. Environmental health 9. Family planning	10. Food safety 11. Health communication 12. Heart disease and stroke 13. HIV 14. Immunization and infectious diseases 15. Injury and violence prevention 16. Maternal, infant and child health 17. Medical product safety 18. Mental health and mental disorders	19. Nutrition and overweight 20. Occupational safety and 21. Oral health 22. Physical activity and fitness 23. Public health infrastructure 24. Respiratory diseases 25. Sexually transmitted diseases 26. Substance abuse 27. Tobacco use 28. Vision and hearing

Table 4.3 Continued

Healthy People 2020: Intervention, Determinants and Outcomes

1. Access to health services
2. Adolescent Health
3. Arthritis, Osteoporosis, and Chronic Back Conditions
4. Blood Disorders and Blood Safety
5. Cancer
6. Chronic Kidney Disease
7. Dementias, Including Alzheimer's Disease*
8. Diabetes
9. Disability and Health
10. Early and Middle Childhood
11. Educational and Community-Based Programs
12. Environmental Health
13. Family Planning
14. Food Safety
15. Genomics*
16. Global Health*
17. Healthcare-Associated Infections*
18. Health Communication and Health Information Technology
19. Health-Related Quality of Life and Well-Being
20. Hearing and Other Sensory or Communication Disorders
21. Heart Disease and Stroke
22. HIV
23. Immunization and Infectious Diseases
24. Injury and Violence Prevention
25. Lesbian, Gay, Bisexual, and Transgender Health
26. Maternal, Infant, and Child Health
27. Medical Product Safety
28. Mental Health and Mental Disorders

Nutrition and Weight Status

30. Occupational Safety and Health
31. Older Adults
32. Oral Health
33. Physical Activity
34. Preparedness
35. Public Health Infrastructure
36. Respiratory Diseases
37. Sexually Transmitted Diseases
38. Sleep Health
39. Social Determinants of Health
40. Substance Abuse
41. Tobacco Use
42. Vision

Sources: Healthy people 1990, 2000, 2010, 2020 (November 2010)
Healthy People websites for each report.
* Indicates a new priority in HP 2020, different from those of previous years.

As seen in Table 4.3 the number of priorities increased every year; the HPR 1990 and HPR 2000 reports are organized similarly with the same headings; HPR 2010 and HPR 2020 do not separate their areas into categories; and HPR 2020 focuses on interventions, determinants and outcomes.

To compare and contrast the 4 reports, Table 4.4 contains the names of the reports, overarching goals, and the definitions of health disparities used in each report.

Table 4.4: *Healthy People Reports goals and their definitions of disparities*

Reports	**Overarching goals**	**Disparities definitions**
Healthy People 1990: Promoting Health, Preventing Disease	-Decrease mortality: infants-adults -Increase independence among older adults	Gaps between the majority and minority populations. The definition includes some age groups, members of certain racial and ethnic groups, people with low income, and people with disabilities, and characterizes these groups as those that "have historically been disadvantaged economically, educationally and politically" (HP 2000, P.45).
Healthy People 2000: National Health Promotion and Disease Prevention	-Increase the span of healthy life for Americans -Reduce health disparities among Americans -Achieve access to preventive services for all Americans.	Differences between majority and minority populations (HP 2000, 9).
Healthy People 2010: Understanding and Improving Health	-To increase the quality and years of healthy life -To eliminate health disparities	Disparities are "believed to be the result of complex interaction among genetic variations, environmental factors, and specific health behaviors" (p.12).

Table 4.4 Continued

Reports	Overarching goals	Disparities definitions
Healthy People 2020: Healthy People in Healthy Communities	-Attain high quality, longer lives free of preventable disease, disability, injury, and premature death. -Achieve health equity, eliminate disparities, and improve the health of all groups -Create social and physical environments that promote good health for all -Promote quality of life, healthy development, and healthy behaviors across all life stages	"Although the term "disparities" often is interpreted to mean racial or ethnic disparities, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen in a greater or lesser extent between populations, there is disparity. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health. It is important to recognize the impact that social determinants have on health outcomes of specific populations" Source: http://www.healthypeople.gov/2020/about/disparitiesAbout.aspx.

Source: Based on Healthy People Reports, as seen on reference list.
The definitions may be in Italics because they were italicized in the original Analysis of Healthy People Reports by Overarching Themes

Analysis of Healthy People Reports by Overarching Themes

In this section I focus on how each report influenced the construction of health disparities. Because in critical discourse analysis the structure of discourse is important in deducing underlying values, I pay particular attention to the language used, and the assumptions it reflects. I analyzed the reports based on 5 main questions to arrive at how the social construction of health disparities was accomplished and implemented:

1) Does the report focus on health disparities, and if so, how does it define them?

2) What are the assumptions underlying solutions and recommendations?

3) Does the report focus on health from a biomedical standpoint or, as a broader state of wellbeing? How does the focus affect proposed solutions (e.g., focus on treatment vs. primary prevention)?

4) Does the report place responsibility for health mostly on individual behaviors, or on systemic conditions? How does locus of responsibility affect recommendations?

5) Does the report acknowledge the effects of both race and class or of one over the other? How does it characterize/define race and class?

By considering the five areas outlined above I aim to uncover the assumptions behind the social construction of health disparities, the prevalence of those constructions and whether the focus chosen contributes to shedding light on, or obscuring the reasons why health disparities continue to be prevalent through time.

Healthy People 1990: Promoting Health, Preventing Disease. This document, which focuses on “A Healthier America,” was driven by scientific research from health experts, and included public input. It de-emphasizes disease treatment by focusing on primary prevention strategies at 5 different life stages – infants, children, adolescents and young adults, adults and older adults.

Primary prevention as a focus sets a tone for defining health as more than health care. The focus on health as broader than the absence of disease is also clear in the way the report prioritizes risks to health and only starts addressing specific diseases in the middle of the 4th chapter. These foci are clearly articulated in the following two statements:

> The objectives focus on interventions and supports designed primarily for well people; to reduce their risks of becoming ill…Thus, few of the objectives deal with secondary prevention (HPR 1990 Objectives, ix). And
>
> The potential to reduce these tragic and avoidable deaths lies less with improved medical care than with better Federal, State, and local actions to foster more careful behavior, and provide safer environments…We need to re-examine our priorities for national health spending… prevention saves lives, improves the quality of life, and it is cost-effective (HPR 1990 1-9,10).

The excerpts above reinforce the assumptions of the importance of primary prevention, and health as wellbeing and more than medical care.

The theme of individual responsibility for health appears in all the documents. It is clear that it is an important part of the discourse in health in the United States. However, there is a different way in which this theme is treated in different decades. For example, in HPR1990, when it mentions individual responsibility, it is often followed by recognition that individual responsibility is limited.

> This is not to suggest that individuals have complete control and are totally responsible for their own health status. For example, although socioeconomic factors are powerful determinants, individuals have limited control over them, nor can they readily decrease many environmental risks. The role of the individual in bringing about environmental change is usually restricted to that

> of the concerned citizen applying pressure at key points in the system or process. But the individual must rely in large part on the efforts of public health officials and others to reduce hazards” (HPR 1979, 2-7,8). And,
>
> To imply, therefore, that personal behavior choices are entirely within the power of the individual is misleading. Yet, even awareness of risk factors difficult or impossible to change may prompt people to make an extra effort to reduce risks more directly under their control and thus lessen overall risk of disease and injury. Healthy behavior, including judicious use of preventive health care services, is a significant area of individual responsibility for both personal and family health” (HPR 1979, 2-8).

However, the words used minimize the strength of the paragraphs. For example, words such as “readily,” “in large part,” and “more” weaken the meaning and impact of the statements. In the end, sentence construction makes the statements appear softer and it could be interpreted as an effort to say something but then soften it to minimize structural determinants of health.

In spite of the weakness of the language, this report explicitly expresses concern about blaming the victim, and emphasizes the role of government:

> Issues often raised in connection with the advocacy of adoption of prevention measures include the appropriate role of government in fostering personal behavioral change; the philosophy and psychology of throwing responsibility for serious health problems back to the victim; the role of business and industrial processes in health and disease; the preferential treatment of

> certain categories of people for insurance purposes; the role of government be regulating the protection measures" (HPR 1990 Objectives xiii-xiv).

The Objectives Report, a companion to HPR1990 is organized to examine, among other elements, the status of a problem, the principal assumptions underlying how the objectives were framed, the measures to address the problem taking into account not only education and information but also legislative and regulatory, plus economic initiatives. There is an explicit effort throughout the report to balance individual, community/institutional and government responsibilities. As part of this more balanced approach personal life choices are presented by explaining that minor changes in behavior can reduce risks for more than one disease, and deciding to reduce one risk for one disease reduces it for others.

This report also considers the fact that lifestyle choices are made in a societal context that is not conducive to good health. For example:

> People must make personal choices, too, in the context of a society that glamorizes many hazardous behaviors through advertising and the mass media. Moreover, our society continues to support industries producing unhealthy products, enacts and enforces unevenly laws against behaviors such as driving while intoxicated, and offers ambiguous messages about the kinds of behaviors that are advisable (HPR 1979, 2-8).

Here, the report acknowledges the role of society as exemplified by the media, government support of industry damaging to health, uneven law enforcement and ambiguous messaging, in affecting the "choices" that individuals make.

Regarding the role of the individual, while the report exhorts individuals to make efforts to reduce their risks, it also recognizes that individuals do not have control over their environment, and it explicitly addresses collective rights and implies government responsibility as in considering “Questions of individual and collective rights and responsibilities, …trade-offs between economic and health values, and of short run versus long run benefits” (HPR 1990 Objectives, xiii). Mentioning collective rights acknowledges society’s responsibilities.

HPR1990 also acknowledges the role of the physical environment, and in doing so, responsibility of decision-makers:

> For decision makers in the public and private sector, recognition of the relationship between health and the physical environment can lead to actions that greatly reduce the morbidity and mortality caused by accidents, air, water and food contamination, radiation exposure, excessive noise, occupational hazards, dangerous consumer products and unsafe highway design (HPR 1990, 1-13).

In this quote, there is a clear recognition that elements not under the control of individuals affect health.

In terms of race and class, HPR 1990 does not emphasize one over the other. Instead, it defines disparities in a broader way that includes all groups that have been historically marginalized economically, educationally and politically.

Healthy People 2000: National Health Promotion and Disease Prevention. This report was developed with participation from a large number of stakeholders from across the country. It focuses on the concept of individual responsibility as a core value. Two main statements that appear in the foreword by the Secretary of the Department of Health and Human Services (Louis Sullivan, MD) set the tone of this report. The first statement says:

> First, personal responsibility, which is to say responsible and enlightened behavior by each and every individual, truly is the key to good health. Evidence of this still-evolving perspective abounds in our concern about the dangers of smoking and the abuse of alcohol and drugs; in the emphasis we are placing on physical and emotional fitness; in our growing interest in good nutritional practices; and in our concern about the quality of our environment. We have become, in a word, increasingly health-conscious, increasingly appreciative of the extent to which our physical and emotional well-being is dependent upon measures that we, ourselves, can affect (HPR 2000, 6).

The second statement says:

> Medical care, alone, will not eliminate the devastating impact of chronic disease on the disadvantaged, nor will it reduce, as much as we would like, the rate of infant mortality or the burden of homicide and violence or any other “health” problems that are borne by the poor in our society. If we are to extend the benefits of good health to all our people, it is crucial that we build in our most vulnerable populations what I have called “a culture of character,” which is to say a culture, or a way of thinking and being, that actively promote responsible behavior and the adoption of lifestyles that are maximally conducive to good health. This is “prevention” in the broadest sense. It is also an absolute necessity, both because we are a humane and caring society and

> because, if we are to remain a vital society, we cannot afford to waste human resources. Good health must be an equal opportunity, available to all Americans (HPR 2000, 6).

The first statement clearly places individual actions as the most important determinant of health. It explicitly ascribes responsibility for health to the individual alone, does not acknowledge that the social context affects the choices people can make, and in fact, blames individuals in disadvantaged populations for their own poor health. In the second statement, the writer also emphasizes “responsible behavior” and portrays “the disadvantaged” as acting irresponsibly and lacking character. The words denote that character flaws are responsible for poor health. These two statements set the tone for the entire report where there appears to be very little recognition of the fact that many features of the environments in which people live determine, to a great extent what “measures” they can affect. The statements also imply that disadvantaged people are inferior. I would consider the characterizations in the above 2 statements as class and racial formation efforts. They paint the poor and racial and ethnic communities as undeserving. And then they couch these pronouncements under an aura of concern, compassion and equality.

HPR 2000 explicitly focuses on prevention of specific major chronic illnesses, injuries and infectious diseases. This focus then places the major concern of the report with health care above a broader definition of health and well being, and with secondary over primary prevention. Additionally, prevention in this report often focuses on teaching individuals how to change their behavior

Even though “reducing health disparities” is presented as one of the overarching goals of HPR 2000, it defines disparities vaguely as differences between majority and minority populations. The report also characterizes minorities as “special populations” at high risk (HPR 2000, 29), not as populations who, because of systemic conditions may be at high risk.

HPR 2000 makes the connection between poor health and lower socioeconomic status, and it does not address racial and ethnic populations as a separate category other than as part of “vulnerable populations”; it is prescriptive, with health recommendation tables for every age group in which diet and exercise are always emphasized, consistent with its premise that the best interventions include education aimed at teaching people at risk how to act (behave, eat, and exercise), as illustrated in the following:

> Health promotion strategies are those related to individual lifestyle—personal choices made in a social context—that can be a powerful influence over one’s health prospects. These priorities include physical activity and fitness, nutrition, tobacco, alcohol and other drugs, family planning, mental health and mental disorders, and violent and abusive behavior. Educational and community-based programs can address lifestyle in a crosscutting fashion (HPR 2000, 6).

Even when the environment is mentioned, the assumption continues to center on the individual: ”Achievement of the agenda depends heavily on individual behaviors. It requires use of legislation, regulation, and social sanctions to make the social and physical environment a healthier place to live” (HPR 2000, 8). I underline “social sanctions” because it denotes that they might be necessary for individuals to behave in certain ways.

Healthy People 2000 includes a section on health protection that focuses on communities rather than individuals, which could be interpreted as an effort to address determinants of health at a broader level. However, it is clear that changing the focus from individuals to communities still leaves unmentioned government action to change structural elements such as poverty, racism and inequality. The discourse may include institutions and even expand on their role, but only insofar as they influence individual behavior, as in the following:

> The challenge facing adults as individuals is to modify their lifestyles to maintain health and prevent disease. But even in adulthood, individual decisions are subject to many forces. Lifestyles once established are difficult to change, addictions even more difficult. Resolution of many of these difficulties is compounded by factors beyond the control of individuals. Socioeconomic status, the environment, community norms, media images and coverage, advertising, worksite standards, access to healthcare and counseling are powerful influences on adult behavior. So the other challenge facing adults, as members of society, is to work together to create an environment that facilitates and supports healthful behavior (HPR 2000, 23).

The above statement could be considered contradictory to the ones previously presented. However, if carefully examined, it seems to speak in circles by including structural elements but only to get back to the role of “healthful behavior.”

The report – HPR2000 – has a section on government where it states that policy decisions can affect health and the environment; however, it avoids talking about regulation of industries and instead mentions partnerships with the private sector, and the role of the states (this, in my opinion, takes responsibility away from the federal government). It does not mention the need for policies that address structural issues like wages, or labor practices, or regulation of corporations. Instead, it emphasizes partnerships with the private sector, and support for biomedical research that points to its focus on health care vs. health. I should mention that the section on government is part of the section on shared responsibilities, considered in the following order: 1) Personal responsibility as “the starting point and ultimate target” of HPR 2000. 2) The family, “as the best resource for the individual.” 3) Community “to encourage healthy life styles.” 4) Health professionals. 5) Media, and, 6) Government.

In summary, the social construction of health disparities in HPR 2000 is based on a narrow definition of disparities as differences between majority and minority populations; it emphasizes health care over health, individual responsibility over societal and government responsibility, and dedicates a section to “special populations” that include people with low income, Blacks, Hispanics, Asians and Pacific Islanders, American Indians and Alaska Natives and people with disabilities. In this last section, the first and major recommendations usually start with individual interventions about physical fitness and/or weight reduction. The report does not mention improving income or dealing with discrimination, or any of the major structural causes behind health disparities. Health disparities are not contextualized within social structures that produce those health disparities by creating systemic disadvantages for certain groups and advantages for others.

Healthy People 2010: Understanding and Improving Health. This document focuses on disease, and centers on individuals. Not only does it continue its predecessor's emphasizes on individual behavior changes, but it emphasizes personal responsibility, mostly devoid of context, consistently throughout. For the first time it introduces the concept of Leading Health indicators (LHI's), defined as reflecting the major public health concerns. Although the report describes and illustrates well the important influence of income and education (HPR2010, 24), it does not include recommendations to address the disparities in health from unequal distribution of these two variables. This report has more objectives than the previous ones and presents two major goals: 1) increasing the quality and years of healthy life and 2) eliminating health disparities.

In the second paragraph of the report, Dr. Donna E. Shalala, Secretary of Health and Human Services, presented the vision of the report as: ”Healthy People in Healthy Communities“ as an opportunity for individuals to make healthy lifestyle choices for themselves and their families (HPR 2010 Message from the Secretary). Clearly, she placed responsibility for health first and foremost on the individual. However, just a few lines later, we read:

> Over the years, it has become clear that individual health is closely linked to community health--the health of the community and environment in which individuals live, work, and play. Likewise, community health is profoundly

> affected by the collective beliefs, attitudes, and behaviors of everyone who lives in the community (HPR 2010, 3).
>
> Or,
>
> Whatever your role, this document is designed to help you determine what you can do—in your home, community, business or State—to help improve the Nations' health (HPR 2010,4).

These two messages, even though they mention community and Nation, emphasize individual responsibility. In addition, the two statements are disconnected and contradictory. One privileges individual responsibility for health; the other one acknowledges the role of the environment and uses language such as "environment in which individuals live, work, and play," usually associated with the social determinants of health. However, immediately after, the emphasis goes back to individual behaviors.

HO 2010 amply illustrates – with statistical information presented in clear charts – that differences in life expectancy, quality of life and self-reported health are substantial among different populations due to "… complex interaction among genetic variations, environmental factors, and specific health behaviors" (p.12-15). It also describes disparities in many areas by education and income, and sometimes by race and ethnicity. However, there are no suggestions or recommendations about how to, for example, reduce income inequality or improve educational attainment.

The report states that to achieve health equity a multisectoral approach will be needed, implying collaboration from different systems. However, it appears to contradict itself by then saying "… the greatest opportunities for reducing health disparities are in empowering individuals to make informed health care decisions and in promoting communitywide safety, education, and access to health care.” HPR 2010, in principle, argues that “every person …deserves equal access to comprehensive, culturally competent, community-based health care systems that are committed to serving the needs of the individual and promoting community health” (HPR 2010, 16). In these statements there is an underlying assumption that health is about health care services, not about wellbeing, enhanced by the omission of most other social determinants of poor health.

Under the section on determinants of health, biology and individual behaviors are mentioned first. A statement about how “social and physical environments that affect the life of individuals, positively and negatively, [may] not be under their immediate or direct control” appears to point to structures in society, and two subsequent paragraphs address environmental hazards, as well as safe places for work and play, and policies and interventions that can have powerful effects on health. Immediately after, the report goes on to emphasize access to health care, again prioritizing health care over health, in apparent contradiction to the previous statement.

In one section of the HPR2000 report I found a definition of health as “a state of physical, mental, and social well-being and not merely the absence of disease and infirmity” (HPR2010, Vol. 1, section 7, p.28), which is the standard definition by the World Health Organization (WHO). However, not much of the report applies this definition, focusing instead on health care. This same section also includes a definition of social ecology: “…the complex interactions among people and their physical and social environments and the effects of these interactions on the emotional, physical, and social well-being of individuals and groups” (7-30); however, again, this definition is not connected to either objectives or recommendations in the report, and the social environment is mostly described as the families and communities in which people grow, while the political or economic environments, important determinants of health are consistently omitted.

Recommendations are organized around the ten Leading Health Indicators (LHI’s), 7 referring to individual behaviors and 3 to systemic issues. Table 4.5 lists the LHI’s, and the objectives developed to address them, by individual and systemic level.

Table 4.5: *Healthy People 2010: Leading Health Indicators and Recommendations*

Leading Health Indicators	**Individual Level Objectives**	**Systemic Level Objectives**
Physical activity	Increase proportion of individuals who engage in physical activity	Exercise recommendations
Overweight and obesity	Reduce proportion of obese individuals with healthy diet and exercise	Promulgation of dietary guidelines
Tobacco use	Reduce cigarette smoking	None
Substance abuse	Reduce alcohol and illicit drug use	None
Responsible sexual behavior	Increase adolescent abstention and condom use	None
Mental health	Increase treatment for depression	None
Injury and violence	Reduce rates of motor vehicle crashes/ Reduce homicides	Increase use of safety belts Toll-free number for poison control

Table 4.5 Continued

Leading Health Indicators	Individual Level Objectives	Systemic Level Objectives
Environmental quality	Reduce proportion of persons exposed to ozone danger, and to tobacco smoke	Improve air quality and understanding threats to exposure to hazardous substances
Immunization	Increase childhood immunization and adult vaccination for influenza and pneumococcal disease	Recommendations for universal administration for at least 5 years
Access to health care	Increase proportion of insured, of persons with ongoing source of care, and prenatal, first trimester care	None

Source: Author, from Healthy People Report 2010, pp 26-45

The table illustrates the omission of objectives to address the structural causes of most of the LHI's from HPR 2010. When systemic recommendations are mentioned, they are only cursorily addressed. The sections about LHI's describe the incidence of the problems, trends and their health consequences. Each LHI presents two or three objectives but no guidelines about how to meet them, other than prescriptive exhortations for healthy diets and exercise. The sections mention barriers to attaining objectives but no solutions at government level such as better regulations of tobacco or labeling of ingredients in food, for example, or ways to deal with issues such as lack of economic resources and lower educational attainment. These two major structural issues are only mentioned as contributing to some LHI's and health problems, not as root causes.

Volume 1 dedicates a large section to extensively examine the proposed objectives for focus areas, baselines and ways to measure progress, progress to date, data and information systems, resources and references from government and academic research. However, there were no suggestions about how to improve the social conditions underlying the higher risks that may be responsible for the health disparities that this report vowed to eliminate.

The determinants of health, defined as “the environment in which individuals live, work, and play” (p.3) form a subsection of HPR2010. However, this language did not reflect the definition of social determinants of health from the broader perspective of the Commission on Social Determinants of Health of the World Health Organization (WHO, 2008). Similarly, although disparities are a major theme throughout, and income inequality and its effect on health outcomes is mentioned with more frequency in this report than in the previous ones, once again there is no mention of how disparities and income inequality are created structurally in society, and therefore no recommendations directed at changing societal conditions.

In summary, consistent reminders of the responsibility of individuals for their own health, omissions of collective and government responsibility, and focus on health care and treatment in HPR 2010 combine to construct health and health disparities as an individual, depoliticized problem to be addressed by the individual victims of inequalities. Reading this report, in its own way very comprehensive and containing extensive sections supported by research and literature, it is difficult to comprehend how its objectives and recommendations are missing the social conditions that contribute to health and illness. It also lacks guidance on how to reach the objectives it proposes. However, in the midst of so much authoritative information, backed up by statistics, graphs, and extensive research, it is easy to miss the omissions.

Healthy People 2020: Healthy People in Healthy Communities.

> The values of a nation are reflected in its willingness and ability to secure better health, wellbeing, and vitality for all. Healthy People must inspire with the spirit of its reach; encourage with its sense of the possible; compel actions…highlight the determinants of health; and lay bare the unacceptable (HPR 2020 Phase I Appendix 2, 53).

Healthy People 2020 started with an Advisory Committee of 13 nationally known experts that recommended the format, framework and guidelines. The product differs significantly from previous reports in form and contents, starting with its availability on an interactive Website. The goal was to make the report “searchable, multi-level and interactive” (HPR 2020 Phase I), and capable of being tailored to readers’ needs. It is not available in print, although it is printable.

Source: US DHHS, November 20, 2010. Accessed at: “www.healthypeople.gov.”

The use of computer technology, lots of color, attractive pictures and fonts, and engaging language make HPR 2020 easily legible and accessible. In addition to form, the content of the report is “inspirational and action-oriented.” The vision statement for HPR 2020 posits “A society in which all people live long, healthy lives” (HPR 2020 Phase 1, 20). The goal sections define the “what” with a clear presentation of definitions, followed by the “how” with specific and concrete guidelines covering issues such as environmental justice and often followed by the ‘who” and “why.” This format is easy to follow and presents clear ways of how to attain the stated goals, and it contains seeds of accountability. The above graphic exemplifies the color and images in the report.

Instead of 10 LHI’s, HPR 2020 has 26, and they are framed in terms of the social determinants of health with different underlying assumptions, as can be seen in the following:

> Recognizing that factors related to social and physical environments, multi-sector policies, individual behaviors, health services, and biology and genetics influence the ability of individuals and communities to make progress on these indicators, the LHI’s will be examined using a health determinants perspective. Addressing determinants is key to improving health disparities and overall population health (HPR 2020, Nov. 2010).

The above statement clearly signifies a change in discourse from HPR 2000 and HPR 2010. In HPR 2020 individual behaviors are only one piece of a big picture of health; health determinants are broadly defined, consistently addressed and applied; and population instead of individual health is at the core of the framework.

The definition of health disparities in Healthy people 2020 is more inclusive than in any of the previous reports:

> If a health outcome is seen in a greater or lesser extent between populations, there is disparity. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health. It is important to recognize the impact that social determinants have on health outcomes of specific populations (HPR2020 Source: http://www.healthypeople.gov/2020/about/disparitiesAbout.aspx). For the first time in Healthy People Reports we find a broad definition of health disparities that includes contextual elements that contribute to good health, and that emphasizes the importance of the social determinants of health.

The following statement, also referring to disparities, is important because it is underscored by an assumption that populations affected by disparities in health "have suffered from systematic disadvantages such as exclusion and discrimination" (HPR2020, November 2012). Exclusion and discrimination are new terms not found in previous HPR reports. This difference in language – tone and meaning – is noteworthy because it denotes an important change, where disparities are not just differences, but are explained within a social structure where some groups are systematically excluded, the disparities are not only by race and ethnicity, and not the responsibility of individuals alone.

This report also differs from previous ones in its approach to prevention, where it defines health in the broader sense of total wellbeing, not only the absence of disease. The first statement to this effect on the report says: "[The report] should redirect our attention from health care to health determinants in our social and physical environments” (HPR2020 Phase I October 2010, 7). In a different section the report makes several references to prevention and health promotion definitions that also set a different tone from HPR 2000 and HPR 2010.

Prevention is treated in this report as a basic tenet, and also specifically differentiated from the definition in HPR 1990, where primary prevention was defined as referring to well people. In HPR 2020 we read instead:

> Health promotion and disease prevention apply to all people, not only those without evident health problems. Even people with significant diseases that cannot be prevented or cured with the application of current knowledge can benefit from health promotion and disease prevention efforts that slow functional declines or improve the ability to live independently and participate in daily activities and community life (HPR 2020 Phase I, October 2010).

This inclusive statement extends the concepts of disease promotion and prevention.

The change in focus from individual to population health and from individual to collective responsibility influences the view of prevention to include much more than change in individual behaviors. In this report complex interactions are considered. As an example: “A mix of preventive and treatment or remedial strategies is needed to alter the complex dynamics of biological, environmental, and behavioral factors that contribute to the development and progression of chronic diseases and conditions (HPR 2020, Phase I, 8). Here we find acknowledgement of the complexities of population health requiring more than individual behavioral changes.

Although the term disparity is frequently used, it appears to be more a measure of preventable differences, and the concept of health equity is amply defined and applied to policies and other elements considered determinants of health. For example:

> Assessing health equity would require measuring changes over time in disparities in health status, health care, and the physical and social determinants of health especially in relation to institutional policies and practices. As one approaches health equity, health disparities become smaller. Over the past 15 years, considerable work has been undertaken to monitor progress toward eliminating disparities. The data and methods that have been compiled in this body of work should guide future efforts to measure health equity (HPR 2020, Phase I, 8).

The above statement clearly differentiates between disparities and inequities.

Healthy People 2020 recognizes the historical focus on individual determinants of health, and the different emphasis it will place:

> Because significant and dynamic inter-relationships exist among these different levels of health determinants, interventions are most likely to be effective when they address determinants at all levels. Historically, many health fields have focused on individual-level health determinants and interventions. Healthy People 2020 should therefore emphasize health-enhancing social and physical environments (HPR2020, Phase I, 9).

In the above, we can see an explicit recognition of the need to address levels other than the individual, which is a different approach from the previous HPR reports.

In this report it becomes clear that underlying assumptions of health equity and the importance of the social determinants of health affect every aspect of how health is conceptualized, from how health is defined as more than health care, to how responsibility for health is distributed, to the role of policy and societal structure, to how solutions and interventions are envisioned. The following statement illustrates how these themes come together:

> Responsibilities for promoting healthful environments go beyond the traditional health care and public health sectors. Changes in social environments, physical environments, and policies can affect entire populations over extended periods of time and help people to respond to individual-level interventions. Policies that can increase the income of low-income persons and communities (e.g., through education, job opportunities, and improvement in public infrastructure) may improve population health. Reducing inequalities in the physical environment (e.g., access to healthful foods, parks, and transportation) can also improve key health behaviors and other determinants, thereby helping to meet numerous health objectives (HPR 2020 Phase I, 9).

Health promotion and health prevention themes appear throughout all the reports with somewhat similar definitions. In HPR2020 the stated definition is significantly more comprehensive and explicitly addresses structural factors. “Long term investments in upstream strategies (i.e., addressing factors that are rooted in broad social systems, and processes that are beyond the control of individuals or specific sectors) are as important as strategies that focus on shorter-term clinical prevention and other direct services to individuals" (HPR 2020, 23).

I am including the definition of health promotion in this report because it sets it apart from previous reports in a major way:

> Health promotion is a process of enabling people to increase control over their health and its determinants, and thereby improving their health. On a global scale, guiding principles in health promotion include: empowerment of individuals and communities for health promotion; achievement of health equity; development of infrastructure for health promotion; social responsibility of the public and private sectors in promoting health; partnerships, networking and building alliances for health; and improvement of individuals' attention to their own health" (HPR2020, Phase I, 23).

The above is a noteworthy statement for several reasons: it invokes international guidelines; it exhorts empowerment of the individual, as opposed to responsibility and blaming; it includes health equity; and it speaks of infrastructure and social responsibility, concepts absent in HPR 2000 and 2010.

HPR2020 defines social conditions as:

> …Including but not limited to: economic inequality, urbanization, mobility, cultural values, attitudes, and policies related to discrimination and intolerance on the basis of race, gender, and other differences. At the national level, other conditions might include major sociopolitical shifts such as

> recession, war, and governmental collapse. The built environment includes transportation, water and sanitation, housing, and other dimensions of urban planning (HPR 2020, 27).

All the reports mentioned “social conditions” but never defined them in such a comprehensive way as in this one. The discourse in HPR 2020 includes intolerance and discrimination and the changing political and economic conditions in society that have strong impacts on health. I consider this shift in discourse an example of a construction of health contextualized in a social, political, and economic environment, a far distance from the earlier decontextualized constructions of health.

Here I include the definitions of health disparity and health equity offered in HPR2020:

> A health disparity is a particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health, cognitive, sensory, or physical disability, sexual orientation, geographic location, or other characteristics historically linked to discrimination or exclusion... in this document, the term refers to a particular type of health difference between individuals or groups that is unfair because it is caused by social or economic disadvantage (HPR2020, Phase I, 28).
>
> Health equity...entails special efforts to improve the health of those who have experienced social or economic disadvantage…is oriented toward

> achieving the highest level of health possible for all groups" (HPR2020, Phase I, 28).

In the section about goal 2, to: "Achieve health equity and eliminate health disparities" the report clarifies that both short- and long-term actions will be necessary to achieve health equity. Among three actions, it includes redistribution of resources: "Distribution of the social and economic resources needed to be healthy in a manner that progressively reduces health disparities and improves health for all." And it also includes root causes in a following action: "Attention to the root causes of health disparities, specifically health determinants" (HPR2020, Phase I, 28-29). This statement departs significantly from previous reports that did not address redistribution of resources.

Elements omitted in previous reports are explicitly and boldly included in HPR 2020. For example: it contemplates resource distribution; it addresses root causes; it pays attention to corporate and government policies as important because of their impact on health and behaviors; and it considers changes in the physical environment, among others. In addition, the report recognizes the importance of partnering with entities not engaged in HPR before, as shown in a statement I found under recommendations for implementation, as one of 6 suggestions on "how to jump start and support innovation" by "Partner[ing] with non-traditional organizations, agencies and initiatives whose focus has been on social justice, human rights and equity" (HPR 2020, Phase II, 7/26/2010 Accessed at: http://www.healthypeople.gov/2020/about/advisory/Reports.aspx). HPR 2020 contains words and concepts that were not present in any of the previous reports, such as social justice and human rights.

In sum, Healthy People 2020 supports a very different construction of health disparities. Here we no longer find the repeated focus on individual responsibility or interventions dedicated to changing individual behaviors with information and education alone. Instead, this report offers complex, new and comprehensive definitions of disease prevention and health promotion. Instead, we find a focus on broad and comprehensive determinants of health throughout the report.

Government, corporations, and institutions other than health systems are held accountable for the large role they play in promoting healthy environments that can be conducive to, not only improved population health, but to achieving equity. The equity framing of this report is noteworthy because it fundamentally changes both the conceptualization of policies, measures and practices, and the discourse that influenced the previous construction of health.

Conclusions

As I delved into the analysis of the Healthy People Reports trying to clarify how they influenced the social construction of health, critical discourse analysis tools helped alert me to elements in the discourse that either addressed the problems or perpetuated them. I looked for what lay between the lines; what was emphasized; what was omitted; the interests served; the hierarchies considered; the voices heard; the ones absent; and the predominant ideas expressed in the documents. With these tools I was able to discern the hegemonic values that prevailed, and the racial formation process that operated, as illustrated in the assumptions that guided the themes I found, particularly in HPR 2000 and 2010, and the competing values that, often, resulted in contradictory statements.

Overarching findings. The first Healthy People Report, published in 1979, when read in conjunction with the three subsequent reports, set itself apart with a focus on primary prevention, risks to health, and a cautious approach mindful of not blaming individuals for their poor health, therefore somewhat balanced between individual, community and government responsibility; and between individual (micro) and structural (macro) elements. The last report, HP 2020, is a stronger document framed on equity and the social determinants of health. In between, HPR 2000 and HPR 2010 focused on individual responsibility and specific diseases, and omitted addressing root causes of disease, as well as systemic disadvantage of racial, ethnic and other populations. It was in these two middle reports that the social construction of health decontextualized from the social, economic, and political environment and entirely lacking social justice solidified. The second of these reports –Healthy People 2010 -, developed in the year 2000, created a definition of health disparities that set a narrow trajectory of objectives and recommendations for the following 20 years.

Contradictions. Predicating health on individual choices (in HPR 2000 and 2010) while ignoring the reality that personal choices are made within a larger context determined by social and economic conditions, resulted in consistent contradictions in the documents. The major contradictions originated in the underlying beliefs about who is responsible for health.

A predominant, hegemonic belief in individual responsibility led to blaming poor health on its victims, expecting individuals to overcome obstacles beyond their control, ignoring growing inequalities in health, income, and educational attainment. Several times these reports documented the kind and extent of disparities in health by race, income and education. However, there were no recommendations to address the inequalities and inequities in these areas. Instead there were several proposals to educate disadvantaged populations about making “good” choices about healthy diet and exercise habits.

The proposals for interventions and solutions did not take into account the social context in which individuals and communities make health choices, and they did not provide sufficient resources or guidelines. This individual locus of responsibility often led to ignoring the role of government and precluded addressing underlying causes of poor health outcomes such as poverty, racism, residential segregation, and concentration of environmental hazards in certain communities and occupations.

Omissions. Emphasizing responsibility of individuals and communities disenfranchised by their social position and living conditions -- in HPR 2000 and 2010 -- often obscured the need for structural solutions geared to solving systemic problems such as poverty and racism. Racism and racial inequality for example, were not mentioned even once in the reports. Poverty was mentioned at times but solutions never suggested. Race, class and power relations were completely omitted as root causes of health disparities and of poor health outcomes.

In summary, the discourse on health changed from HPR 1990, when context was at least acknowledged and government responsibility was considered, to HPR 2000 and 2010 when a hegemonic idea of individual responsibility obscured social, economic and political realities, which led to contradictions and glaring omissions. HPR 2020, in contrast, appears hopeful. It is framed in the social determinants of health and health equity principles that recognize unfairness and emphasize collective and multisectoral responsibility for health in all its complexity.

In the following two chapters I analyze a few other important reports also written in the period of interest for this study, and the interviews with key informants. These additional pieces of evidence will shed more light on understanding the changes in discourse and policies that the sequential HPRs manifest.

The widespread values embedded in North American culture - that we are a nation of individuals where we all have equality of opportunity, we lift ourselves by our own bootstraps and we are responsible for our own fate -, appear to form a hegemonic bubble that appears to pre-empt knowledge, common sense and a basic spirit of solidarity. This hegemonic current seems to underlie the assumptions that resulted in HPR 2000 and HPR 2010 and obscures structural inequalities. However, there is also a counter hegemonic and concurrent belief in community, the value of solidarity and the responsibility of government that seemed to initiate in 1979, went under from 1990 to 2008 and is resurfacing again in the discourse. We have yet to see if the spirit proclaimed in HPR 2020 will persevere and start a new era where equity and fairness prevail.

Chapter 5: Analysis of Other Pertinent Reports

Introduction

In addition to the Healthy People Reports (in the previous chapter), several other documents published between 2000 and 2003 provide a somewhat different perspective on the social construction of health disparities. In this chapter I will analyze:

- Unequal Treatment, Institute of Medicine (IOM), 2003.
- Minority Health and Health Disparities Research and Education Act of 2000 (Public Law 106-525, 106th Congress)
- National Healthcare Disparities Report by the Agency for Healthcare Research and Quality (U.S. DHHS, AHRQ, 2003).
- World Health Reports 2000 that, even though published by the World Health Organization, was influenced by United States policy.

After analyzing each report separately I will synthesize the findings in the conclusion section.

Unequal Treatment

I chose to analyze "Unequal Treatment (UT): Confronting Racial and Ethnic Disparities in Health Care"[12] (Smedley, Stith, & Nelson, 2003) because the 106th US Congress in 1999 requested the study towards the end of President Clinton's administration, the period of interest in this dissertation project. Congress requested

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[12] This is the Institute of Medicine's (IOM) report published in 2003 and written in response to a congressional request made in 1999. Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson edited Unequal Treatment. The Office of Minority Health, U.S. Department of Health and Human Services, funded the study with additional support by The Commonwealth Fund and the Henry K. Kaiser Foundation. The report was published by the Institute of Medicine of the National Academies.

the report from the Institute of Medicine (IOM) in response to findings from a large body of published research revealing that the healthcare experience of racial and ethnic minorities was inferior to that of Whites regardless of insurance coverage or ability to pay, and that the differences in medical care were associated with greater mortality among African-Americans.

The IOM is an independent, nonprofit organization that works outside government to provide objective, straightforward, unbiased and authoritative advice to decision makers in government, the public sector, and the public about health and healthcare.[13] This self-description makes a claim for the agency's standing, legitimacy and status.[14] The fact that Congress requested the study from the prestigious IOM places this document as a prime example of dominant discourse with broad societal influence, which makes it an appropriate piece for my analysis of the social construction of health disparities. However, it should be noted that since the IOM receives an annual appropriation from Congress, some scholars question its independence from government (Gamble & Stone, 2006 p.110).

The 106th Congress charged the IOM with 3 tasks:

- Assess the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage);

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[13] Information retrieved from http://www.iom.edu/About-IOM.aspx December 21, 2011.

[14] However, it should be noted that since the IOM receives an annual appropriation from Congress some scholars question its independence from government influence (Stone & Glasser, 2006).

- Evaluate potential sources of racial and ethnic disparities in healthcare, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels;

And,

- Provide recommendations regarding interventions to eliminate healthcare disparities (Unequal Treatment, 2003.3).

To carry out these tasks, the IOM selected and gathered a group of experts from medicine and public health to review existing literature and to contribute papers as a basis for the report.

The contributing papers requested by the IOM presented a broad range of perspectives about racial and ethnic health care disparities to use as a major part of the scientific literature for developing the "UT" report. As I was reading these papers, I noticed striking differences between the discourse in the papers and in the report. Even though the papers and the report were addressing the same themes, in some instances their interpretations diverged significantly. The first of these reports, by Geiger[15] (Geiger, 2002), is particularly important in the context of the UT report.

Geiger's paper presented the different theories, gathered from a review of 150 papers, about the reasons for ethnic and racial disparities in health. He reviewed the social determinants of health, including historical discrimination that

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[15] Jack Geiger is internationally recognized as an activist because of his involvement as a founding member and former president of Physicians for Human Rights and Physicians for Social Responsibility, and for his participation in human rights efforts and activities related to health, poverty and civil rights in many countries. Dr. Geiger also initiated the community health center initiative in the United States. Accessed at: www.lib.ici.edu/quest/index.pHPR?page=geiger_bio."

stubbornly persists, racist stereotypes that affect treatment of patients from ethnic and racial groups, and essentialist views of race that persist. However, the UT report omitted Geiger's findings and theories about the role of determinants of population health embedded within society's social stratification and the political economy, and many other structural factors contributing to inequalities in diagnosis and treatment of racial and ethnic populations. I include the titles of the contributing papers in Appendix III.

The role of language. I analyze the role of language in the IOM's Unequal Treatment (UT) report because it exemplifies dominant discourse with the power to define and interpret issues, as well as guide policy at the federal level. In fact, even today, 10 years later, this remains one of the most often cited and mentioned IOM reports, and it was very popular when it was published.[16]

Definition of disparities. The title "Unequal Treatment" appears to encompass general treatment of racial and ethnic minorities, but the word treatment only refers to medical treatment in medical settings, a limited meaning. Also limited, "disparities" are defined in a very specified way, based on the mandate from Congress, as: "Disparities in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access related factors or clinical needs, preferences, and appropriateness of intervention" (Ibid, 3-4). The focus of this IOM

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[16] "When the Institute of Medicine (IOM) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care issued its report in March 2002 [1], it created a stir not unlike the one that greeted the announcement of two other influential, and somewhat controversial reports, the report on patient safety and that on the quality chasm" (Nelson, 2003).

report is therefore restricted from the outset to health care, and, further, only to health care quality.

Inconsistencies in the report. Several pieces of the report seem confusing. One of the most salient examples relates the story of Mr. Tools (as told on page 2 of the Abstract). The report describes Mr. Tools as a 59-year-old African American, and medical miracle. He was the first survivor (even if for a short time) of an artificial heart implant. In this example the authors highlight that the patient was African American; all the doctors were White; and they were very grateful and “honored” that Mr. Tools paved the way for other patients. The doctors also looked at Mr. Tools with “affection.”

I question the prominence of the story of Mr. Tools since it has to do with access to treatment, not unequal treatment, which the theme of the report. On the contrary, the story of Mr. Tools is explained as a proud example of how the fact that all the doctors were White and the patient was Black “seemed to symbolize the irrelevance of race in 2001” (p.2) since a Black man was offered a cutting-edge procedure.

The paragraph following the above story clarifies that, “Behind these perceptions, however, lies a sharply contrasting reality… racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than are White Americans” (UT, p.2)

While the story of Mr. Tools seems strange at first, it is the story often told, of how individuals (in this case a Black patient receiving an advanced procedure from White doctors) are treated fairly regardless of race, presenting an image of fairness and bypassing or covering up systemic issues of discrimination. It is also noteworthy that Mr. Tools died not too long after the procedure, emphasizing that, contrary to what is stated, the indication is that Mr. Tools was not so much a miracle but an experiment.

Restrained and tentative language. The IOM framed the issues according to the mandate from Congress and by the parameters of scientific research. These parameters established the study as a careful assessment of healthcare disparities to be addressed based on findings from peer-reviewed studies. However, I consider the restrained and passive language of the report starting with a definition of disparities that avoids agency, and the regular use of tentative or cautious language, as a way to avoid strong statements about such a concerning and persistent problem, as the inequitable medical treatment of Black patients.

For example, the first line of the abstract in the report says: “Racial and ethnic minorities tend to receive a lower quality of health care than non-minorities” (p. 1). The word “tend” contradicts later statements in the report about the concerns of Congress, and softens the effect of the many peer-reviewed studies cited throughout that present robust evidence of lower quality of care that results in higher mortality rates for minorities. Other tentative words like “may,” in expressions such as “may enhance the likelihood that” are frequently used. Tentative language diminishes the effect of the findings presented.

Passive language. The use of passive language in the document preempts assignment of responsibility for disparities in healthcare, and for remedying them. This shortcoming allows the authors to sidestep structural issues throughout the report. Instead, they choose the narrow focus of individual patient/provider interactions. For example, the definition of disparity as “Racial or ethnic differences in the quality of healthcare “(UT, p. 4) does not assign agency, and does not make any inferences of unfairness or systemic causality. On the contrary, throughout the text, responsibility for inferior care for minorities is often apportioned equally to patients and providers.

Language assigning equal responsibility to providers and patients. When talking about patient-provider interaction, the text infers that inferior medical treatment of minorities is due to “complex” reasons that both patients and providers ought to be responsible for changing. There seems to be an implicit effort to equalize patient and provider in the clinical interaction. How this is done is subtle, yet noticeable. For example, asserting “minorities’ ability” to attain quality health care (p.2) as opposed to “providers’ ability” to provide quality health care assigns equal, if not greater, individual responsibility to the patient as to the provider. This maneuver is repeated throughout the text, where “patients’ role/responsibility” is consistently mentioned either before, or immediately after “providers role/ responsibility” and before “society at large responsibility,” implicitly giving more or equal importance to patient responsibility.

For example, a recommendation to change the unequal environment due to provider bias and stereotypes includes “economic incentives to providers’’ to do the right thing, never mentioning “economic incentives to patients” (p.2) who have received substandard care/treatment due to the inability of providers to treat patients of color equally and/or equitably. The implicit assumption seems to be that it is so difficult for providers to do the right thing for their minority patients that they need economic incentives to do so.

When mentioning education as a way to decrease unequal treatment, patient education and provider education appear as equally valid strategies, once again putting the onus of equalizing treatment on patients as much as on providers. In effect, the report proposes educating patients as well as providers as the solution to biases and discrimination on the part of providers. This solution implies that the patients share responsibility for the biases of providers. Instead, the report could have mentioned more systemic solutions, such as establishing regulations to prohibit unequal treatment of patients or sanctions to providers when this occurs.

Missing elements in the discourse. Unequal Treatment acknowledges that “racial and ethnic discrimination are found in many sectors of American life” (p.7) but does not explicitly acknowledge or name racism and discrimination as determinants of health, or the injustice in the medical treatment of racial and ethnic minorities. Instead, when the report makes a tenuous connection between individual or organization interactions with structural political and/or economic issues, it is often undeveloped and ignored in the recommendations. For example,

> Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable. Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders. And, Recommendation 2-2: Increase healthcare providers’ awareness of disparities (p. 6).

Increasing awareness of the problem appears an insufficient remedy, considering its consequences. It is noteworthy that recommendations like this one and others do not mention who should carry them out.

Or,

> Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life (p. 7).

There was no recommendation for these findings.

When the finding refers to fragmentation of healthcare delivery and financing, the recommendation reads: To "Avoid fragmentation of health plans along socioeconomic lines by equalizing access to high- quality plans" (p. 13). This recommendation does not provide guidance as to how to accomplish this goal, or acknowledgement that the present system is not designed to provide access to high-quality plans for minorities.

When the report acknowledges that systemic conditions such as "high time pressures and pressures for cost containment" contribute to poor care of minorities compared to Whites, the solution focuses on increasing awareness and education. This proposed solution does not address the systemic conditions in clinical practices that cause high time pressures on practitioners.

Strong condemnation of prejudice exhibited by providers with negative health consequences for minorities, including excess and unacceptable mortality, is also missing. Instead, the language belies an attitude of excuses and even sympathy for the behavior of providers, such as: full schedules, uncertainty, and “unconscious” prejudice that cause rush judgments and stereotypes. Furthermore, in spite of the evidence showing bias and prejudice by medical providers, the recommendation states:

> Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research UT, 12).

This recommendation calling for more research on stereotyping and prejudice does not appear sufficient or timely to decrease bias and prejudice on the part of medical providers.

Summary. In sum, by focusing on health care delivery and individual clinical interactions between providers and patients of color, the authors avoid critiquing broader social structural issues. Furthermore, even within this narrow focus, the authors use tentative language and placement of words to minimize or soften the impact of biased and discriminatory practices on the part of medical providers, and equalize their responsibility to that of patients. The report does make a few recommendations to improve relationships between patients and providers by increasing the number of health professionals from minority populations (p. 14), and to apply the same protections for patients in publicly funded and private Health Maintenance Organizations (HMOs). However, these suggestions are vague and do not state who should carry them out or how.

Unequal Treatment amply documents disparities in healthcare; its findings are based on excellent research, as exemplified by the nine papers accompanying it. However, the majority of the recommendations refer to more research, the need for better data, education programs, cultural competence training, and increasing awareness of disparities among the general public, key stakeholders, and providers, in that order, without clarifying who will be responsible for implementing them.

Based on my analysis, Unequal Treatment complies fairly well with its (first) mandate, to assess the extent of racial and ethnic differences in healthcare. The report evaluates potential sources of disparities at the individual provider and patient levels, but does not adequately evaluate institutional and health system levels (second mandate). Unequal Treatment does not make strong, sufficient, or detailed recommendations about who is to carry them out, or when thus failing on its mandate to provide ways to eliminate health disparities (third mandate). The report also fails to address and engage in a discussion of the different levels of intervention necessary for any real change to occur.

I conclude that the focus of the report, methods, and recommendations are in tune with the prevalent ideologies of the time - individual responsibility and health reduced to medical care – when it was developed and published. The ideology of “health disparities” maintains the narrative and discourse focused on the individual level, ignoring systemic and structural issues. Considering that Unequal Treatment was a scientific report, it had authority that could have been used for political leverage. In fact, the UT report was widely disseminated and quoted in academia, government and the media, even years after its publication. However, from its outset, the report was narrowed to only considering health care “disparities” and not to focus on the impact on health of socio-economic structural inequalities. Based on my analysis, I conclude that Unequal Treatment missed a great opportunity to use the scientific findings effectively for political action.

Minority Health and Health Disparities Research and Education Act of 2000

(Public Law 106-525, 106th Congress).

Background. PL 106-525 was one of the ways President Clinton used legislation to put in place some structures to address “elimination of health disparities” in his last term. The law started out as “The Health Care Fairness Act of 1998” and was passed as the “Minority Health and Health Disparities Research and Education Act of 2000.” It is noteworthy that the word “fairness” was not included in the final title.

The first provision of the law elevated the status of the “Office” of Minority Research, which had been created in 1986, to the National “Center” on Minority Health and Health Disparities (a center has greater status than an office). The purpose of the Center was to conduct and support “research, training, dissemination of information, and other programs with respect to minority populations and other populations with health disparities” (PL 106-525, p. 2497).

The law also provided a legal definition of health disparities, based on the definition used by National Institutes of Health: "Health disparities are differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.” In the law, we also find the first detailed legal definition: "A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population" (United States Public Law 106-525 (2000), p. 2498).

The law defines “health disparities research” as: “basic, clinical, and behavioral research on health disparity populations, that relates to health disparities as defined, including the causes of such disparities and methods to prevent, diagnose, and treat such disparities.” The definitions of disparities and research set the parameters that preclude wider research into root causes. For example, a clause requiring a progress report one year after enactment of the law states that the report should:

> Identify the data needed to support efforts to evaluate the effects of socioeconomic status, race and ethnicity on access to health care and other services and on disparity in health and other social outcomes and the data needed to enforce existing protections for equal access to health care (Ibid, 2508).

Clearly, health care seems to be the preferred subject covered within the law.

Missing elements. PL 106-525 is missing several important elements. This law fully focuses on “health care” disparities, not on wellbeing; does not refer to causal conditions; and omits acknowledgement of root causes, such as discrimination and racism.

The law provides for the inclusion of members of communities affected by disparities in “the planning, conduct, dissemination and translation of research” (PL

106-525, 2506). However, at the same time, it restricts the focus of community participation to the confines of health care disparities only, the development of quality measures, and collection of data by race and ethnicity. While measures and data are important, the law misses the opportunity to address structural issues. Thus, the law limits the definition of health disparities and the focus of the research and interventions that followed.

Dissemination. A section of the law (PL 106-525, p. 501) dedicated to dissemination emphatically asserts the importance of involving minorities in the process of disseminating information about racial and ethnic health disparities to the affected minority communities, the affected providers (Ibid, p. 2498), and the NIH agencies. While including these stakeholders as a strategy appears as positive, if we look at what is being disseminated, we find: a narrow definition of disparities that does not include any causality or connection to societal conditions; a consistent focus on health care as the most important aspect of health; the need for more descriptive research; and recommendations limited to educating minorities to teach cultural sensitivity training to individual providers. In sum, what ends up being disseminated are narrow ideas that, in the end, do not contribute to the stated goal of eliminating health disparities, and construct health disparities devoid of causes and social justice. In effect, what is being disseminated is a narrow conceptualization of health disparities.

National Healthcare Disparities Report 2003 by the Agency for Healthcare Research and Quality (U.S. DHHS AHRQ, 2003)

The effort under the Clinton administration to continue to call attention to and “eliminate health disparities” included several initiatives in addition to the report Unequal Treatment and Public Law 106-525. One of these efforts established regular research and support of research to be disseminated in annual reports thereafter by the Agency for Healthcare Research and Quality (U.S. DHHS AHRQ). The National Healthcare Disparities Report 2003 was the first of them, and it was mandated by Public Law 106-129 to engage in and support health disparities research. This report is the subject of my analysis.

The first paragraph of the introduction clearly explains its purpose:

> It [the report] will demonstrate that disparities exist for many Americans and improvement is possible. Rather than offer a series of snapshots of disparities from individual research studies, this report provides a comprehensive view of the scope and characteristics of differences in health care quality and access associated with patient race, ethnicity, income, education, and place of residence. To date, no report had provided extensive cross-group comparisons that could provide a national roadmap with focused efforts to reduce disparities (United States Department of Health and Human Services AHRQ, NHDR, 1).

By the time this report was developed, the IOM’s “Unequal Treatment” had already been published, and a few sentences in the above quote appear geared to differentiate the two reports. Notwithstanding the differences, the IOM report influenced the NHDR report. For example, the NHDR report lists “clinical uncertainty” and “health care practitioner beliefs” – concepts from the IOM report – among factors leading to differences in health care (Ibid, p. 2). However, the writers describe the NHDR as “unique” because it provides a comprehensive overview of differences in health not only by race and ethnicity but also by socioeconomic groups for the first time; and it “capture[s] the relationship between race/ethnicity and socioeconomic position.” Additionally, this report measures disparities from a national perspective (Ibid, pp. 4,5).

The NHDR report repeats several mainstream concepts in the social construction of health disparities during the period of time under study: 1) The definition of disparity as mere difference; 2) the inclusion of lifestyle choices as responsible for healthcare disparities; and 3) the focus on healthcare rather than a broader definition of health.

1) The NHDR’s definition of disparity appears broader, as in the following:

The condition or fact of being unequal, as in age, rank, or degree. Synonyms for disparity include inequality, unlikeness, disproportion, and difference. While disparity in health care has been closely associated with equity, there are several potential reasons for the differences observed at the individual level (Ibid, p.1).

However, again we see here that this definition does not imply anything more than difference, and it equates inequality with difference.

2) The concept of “lifestyle choices,” central to the social construction of health disparities, appears in NHDR as one of the many factors, although not the first, to be considered: “These include different underlying rates of illness due to

genetic predisposition, local environmental conditions, or “lifestyle choices” (Ibid, p. 2) In this same paragraph care-seeking behaviors are listed next, and these behaviors could be considered under the rubric of personal responsibility. However, this report mentions other agents who may also share responsibility for health, as in the following: “there may be differing perspectives regarding the appropriate division of responsibility between the individual, the public sector, and the private sector (Ibid, p. 2).

3) The focus on healthcare is clear. The NHDR focuses on disparities in health care, rather than disparities in health. Here, an underlying assumption is that, by addressing disparities in health care, a great part of disparities in health would also be addressed, as explicitly stated in the following statement:

> Disparities in health care can only be interpreted within the context of disparities in health. Disparities in health help identify critical disparities in health care with which they are associated. Eliminating disparities in health care is a logical method for eliminating associated disparities in health” (Ibid, 17).

The above statement explicitly presents the differences in focus and posits that healthcare is paramount in eliminating disparities in health.

The AHRQ considers the NHDR complementary to “Healthy People 2010” by focusing on health care delivery, and to the IOM’s “Unequal Treatment” report by measuring disparities at the national level, and as a tool that provides “baseline data...to measure the effect on national initiatives to reduce disparities” (NHDR, p.

6). Both the IOM and the NHDR reports provide only descriptive information to document the problem of disparities in healthcare.

The NHDR report makes a noteworthy effort to measure disparities by race and class, and is mindful of how to measure these categories. The report clearly explains methods, and appears to make decisions judiciously, considering the absence of guidelines by the Office of Management and Budget and the limitations in the data about minorities other than Blacks. The report recognizes that, in the absence of consensus on how to specify socioeconomic disparities, researchers use a variety of measures like “income, poverty, education, occupation, wealth, class, and social capital” (Ibid, p. 34) to account for them. The NHDR decided to focus on “family income relative to Federal poverty thresholds and education as commonly used and available measures of socioeconomic position and sought to include both dimensions when feasible” (Ibid. p. 34). However, this report did not pay attention to whether race and ethnicity were measured based on self-classification or assignment by researchers or other third parties. And, in reference to socioeconomic status, the report did not consider other elements – like income level during childhood, parental education, or interactions between constructs.

Unlike previous reports I analyzed, this report calls for research to “improve our understanding of the underlying mechanisms and causal paths that result in disparities” (Ibid, 10) and calls for future reports “to probe the underlying [root] causes of the differences,” that “are likely multifactorial and complex. Identifying them and understanding their dynamics is key to designing effective interventions” (Ibid, 17). However, it also states:

> …The capacity to measure the existence of racial, ethnic and socioeconomic disparities in health care far exceeds the current state of knowledge explaining why such disparities exist and how to reduce them. Given the breadth of the Congressional mandate to provide a national overview of disparities in health care, the NHDR focuses on documenting existing disparities. The first report will provide a baseline from which to track future trends in health care disparities. (Ibid, p. 34).

The first statement recognizes the complexity and multilevel causes of and causal pathways involved in disparities, and the second states that there is limited knowledge to explain why disparities exist and how to reduce them. Therefore this report opted to focus only on documenting disparities. Thus, while the AHRQ considered the NHDR an important step in the process of eliminating health disparities, the report failed address structural inequalities. One of its key guiding principles was consistency with Federal guidelines and publications such as Healthy People 2010 (Ibid, 22).

When the Department of Health and Human Services (DHHS) released the National Healthcare Disparities Report on December 23, 2003, political appointees within the Bush administration had altered it in significant ways. Someone leaked the original draft to the media, and an investigation by the U.S. House of Representatives Committee on Government Reform ensued. As evidenced by the report that presented the results of this inquiry (USHR Report, 2004), the version released:

-- Deleted most uses of the word disparity (or left the term undefined) and used “difference” instead.

-- Stated that “some socioeconomic, racial, ethnic, and geographic differences [did] exist,” instead of the scientists’ assertion that “racial, ethnic, and socioeconomic disparities are national problems that affect health care at all points in the process, at all sites of care, and for all medical conditions.”

-- Eliminated findings on “the social costs of disparities” and instead discussed “successes.”

-- Omitted “key examples of health disparities” that illustrated some of the worst situations scientists had found, such as: “that racial and ethnic minorities are more likely to be diagnosed with late-stage cancer, die of HIV, be subjected to physical restraints in nursing homes, and receive suboptimal cardiac care for heart attacks,” and instead highlighted examples of differences like: “Hispanics and American Indians or Alaska Natives are less likely to have their cholesterol checked” (USHR, 2004, 2).

The alteration of the report denoted political interference to minimize racial and ethnic disparities in healthcare and had the potential further to undermine solutions. It also illustrated a political construction of health disparities based on a particular ideology, even less willing to address the problem as anything other than an individual problem. As Bloche (2004) uncovered in a paper published by the New England Journal of Medicine, changes in the report were not just a mistake, as members of the administration stated later, but were motivated by “a coherent vision.” In the view of those who changed the report, the original report pointed to the need for providers to change their practices, and for government to do things differently, which would “undercut” the message of “personal responsibility” for health outcomes (Bloche, 2004, 1). In effect, those responsible for radically altering the report considered even the word disparities too strong.

This story is ironic because the key documents developed by the Clinton administration also promulgated the message of personal responsibility, and did not address structural causes or government responsibility, as illustrated earlier, This episode demonstrates the pervasiveness of a hegemonic view in both sides of the aisle. However, the fact that someone leaked the report to the media and that Bloche found and disclosed the personal responsibility argument shows the not everyone agreed with the hegemonic current.[17]

As Bloche reported in a previous report,[18] the Bush Administration repeatedly distorted science to promote a narrow political or ideological agenda. Among the examples of political interference cited in the report were “instances of altered websites, suppressed agency reports, erroneous international communications, and misleading statements by senior Administration officials” (USHR, 2004). The altering of the NHDR provides further evidence of the politicization of science at DHHS under the Bush administration. The alterations demonstrated a construction of health designed to absolve the government of responsibility for health disparities and instead, to place responsibility on individuals.

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[17] According to Bloche (2004), an internal memo by one of the persons responsible for the rewrite – Arthur J. Lawrence, principal deputy assistant secretary for health—said that a focus on the system would suggest systemic as opposed to personal responsibility.

[18] Minority Staff, Government Reform Committee, Politics and Science in the Bush Administration (August 2003) (online at www.politicsandscience.org)

World Health Report 2000: Health Systems: Improving Performance

I decided to include WHR 2000 in my analysis to underscore the differences in discourse between the United States and Europe during the same year (2000). Namely, the WHR uses the concepts of equality, equity, and the social determinants of health while the HPR 2010 (written in 2000) only uses the concept of "disparities." In addition, WHR 2000 refers to important international political reforms that affect health equity that none of the HPR reports include. My analysis will focus on a few remarkable characteristics of the WHR 2000.

Starting with the title: "Health Systems: Improving Performance," we know WHR 2000 is different from the other ones included in this study because it addresses responsibility of health systems, as in the following statements:

> Ultimate responsibility for the performance of a country's health system lies with government. The careful and responsible management of the well being of the population – stewardship – is the very essence of good government. The health of people is always a national priority: government responsibility for it is continuous and permanent (WHR, p. viii).

This statement clearly locates responsibility for population health and wellbeing in government. And,

> From the safe delivery of a healthy baby to the care with dignity of the frail elderly, health systems have a vital and continuing responsibility to people throughout the lifespan. They are crucial to the healthy development of individuals, families and societies everywhere (Ibid, p. xi).

Clearly, this report addresses the importance of health systems. At issue here is why weren't HPR reports addressing government system issues? And why did reports in the United States repeatedly omit government as a determinant of health, when these concepts appeared to be accepted internationally?

The WHR explicitly connects "the widening gaps in death rates between the rich and the poor" (Ibid, p. ix) to "differing degrees of efficiency" in organization and financing of their health systems. The report also connects the goal of strengthening performance of health systems to health outcomes: "Strengthening [health] systems … connects very well with [the goal of] … reducing the excess mortality of poor and marginalized populations; dealing effectively with the leading risk factors; and placing health at the center of the broader development agenda" (Ibid, p. xii). WHR 2000 ascribes poor health outcomes to performance failures in health systems.

I also find remarkable in this report the recognition of the influence of political changes from the 1980s on health policy. The report highlights: "transformation from centrally planned to market-oriented economies, reduced state intervention in national economies, fewer government controls, and more decentralization" (Ibid, p. xiv), and what these changes meant politically and ideologically. It explained: "Ideologically, this has meant greater emphasis on individual choice and responsibility. Politically, it has meant limiting promises and expectations about what governments should do" (Ibid, p. xiv). These statements clearly describe the effect of reforms - that took place in the 1980s in the United States - which were hardly, if ever, acknowledged, and definitely not included in Healthy People reports 2000 and

2010. The statement above also clarifies how “emphasis on individual choice and responsibility” resulted from the political and ideological reforms of the 80s.

The above observations constitute an apt description of what occurred in the United States, where, consistently, system failures resulted in the same problems enumerated in WHR 2000:

> … preventable deaths and disabilities… in unnecessary suffering; in injustice, inequality and denial of basic rights of individuals. The impact is most severe on the poor, who are driven deeper into poverty by lack of financial protection against ill health. In trying to buy health from their own pockets, sometimes they only succeed in lining the pockets of others (Ibid, p. xiv).

The language above could easily describe issues documented in the IOM’s “Unequal Treatment” about minority populations, and in the AHRQ 2003 reports about the disadvantaged populations they covered. However, the mild and vague language in the US reports skirts and avoids issues that may be considered controversial. The discourse in WHR 2000 and the reports the United States developed during the same period of time differed remarkably, as illustrated above.

A number of researchers from across the world strongly criticized the WHR 2000 for a number of reasons, mainly centered on its neoliberal ideology, and its utilitarian approach to health as necessary for economic growth, as opposed to health for its own sake. Some critics faulted the report on methodological issues such as insufficient and inappropriately obtained data and thought the report was ideological and with the potential of having negative social consequences (Almeida et al., 2001), rather than being concerned with equity (Braveman, et al., 2001).

Others focused on policy (Navarro, 2001); promoting managed competition and privatization; prioritizing spending in health care; and ignoring social conditions (Navarro, 2002); while still others on overlapping interests with the World Bank and the International Monetary Fund as driving its focus (Waitzkin, 2003).

The shortcomings, errors, and neoliberal ideology of the WHR 2000, as I briefly mention them, are not the focus of this study. However, I found this report useful in comparing differences in discourse between the United States and other parts of the world, in what it seems to be an effort to address deficiencies and contradictions in a system that is dictated by market principles, but that is not acknowledging them and is trying to skirt around them. In the end, an approach that reduces the construction of health inequalities and inequities to health disparities perpetuates the underlying inequalities and resulting inequities. The main point in my argument centers on how the discourse in the United States ignored words and concepts used and accepted in other parts of the world.

Limited Content Analysis

I calculated the frequency of the words “disparity,” “inequality” and “inequity” (e.g.: disparities, inequalities, equity, etc.) in the documents examined, to answer the question of whether language changed from one period to another (before the 1990’s and after). To calculate frequencies I counted the number of times each of the words in question appeared per page instead of the number of words in the document. I used this method because the total number of words per document was not available, while the number of pages was.

Table 5.1 shows the frequency of the words “disparity/ies, in/equality/ies, and in/equity/ies, in numbers, in the years when the Healthy People Reports were written.

Table 5.1: *Frequency of words ‘disparity,” “inequality” and “equity” in Healthy People Reports*

Terms	1979	1990	2000	2010
Disparity	0.004	0	0.25	1.143
Inequality	0	0	0.014	0.05
Inequity	0	0	0.014	0.68
# of pages	262	845	140	98

Source: Healthy People Reports

Based on the above numbers, I calculated the proportional use of the terms in reference to the number of pages per document, and charted them (e.g.. In 1979, disparity appeared 1 time in 262 pages, therefore 1/262= 0.0004). The results appear in Figure 5.1 below.

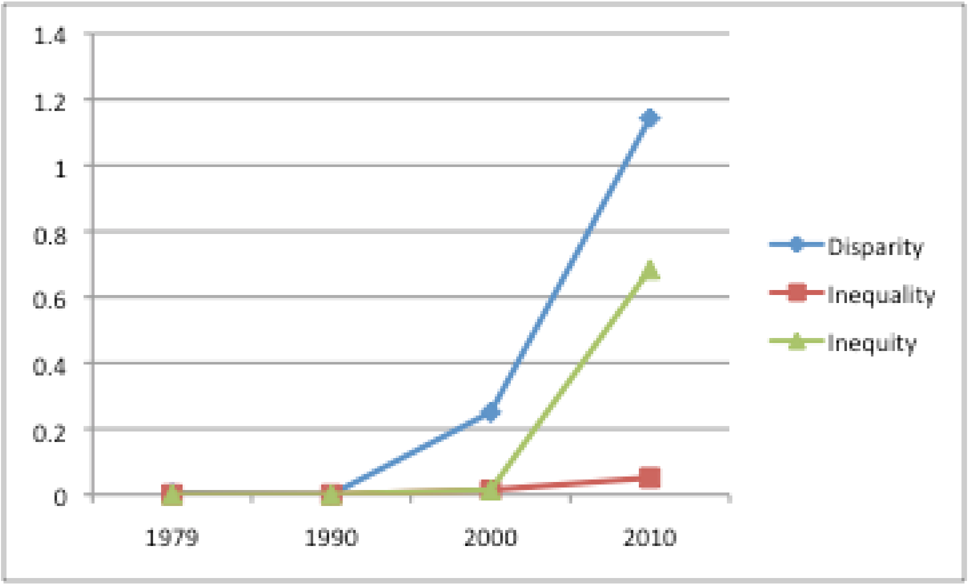


Figure 5.1: **Frequency of words in Healthy People Reports**

Figure 5.1 above clearly illustrates the different proportional use of the words "disparity" (blue line on the left), "inequality" (red line, bottom)) and "inequity" (green line, middle) in the Healthy People Reports (horizontal axis). The vertical axis has percentages (number of times a term appeared on a page compared to the number of pages in the entire report).

Since I analyzed reports other than Healthy People, I also conducted a count of the words in question and calculated the frequency of use. To calculate proportions I divided the number of times the words in question appeared on a page by the total number of pages in the document. Table 5.2 reports the numbers and Figure 5.2 images them.

Table 5.2: *Proportion of Words in Other Reports Analyzed*

Terms	WHR 2000	PL 2001	AHRQ 2003	Unequal Treatment 2003
Disparity	0	8.7060	3.3140	2.560
Inequality	0.4372	0	0.0582	0.1754
Equity	0.1116	0	0.0450	0.0294
# of pages	215	17	223	781

NOTE: Percentages (proportions calculated by dividing the number of times a word in question appeared in the entire document divided by the number of pages in the document).

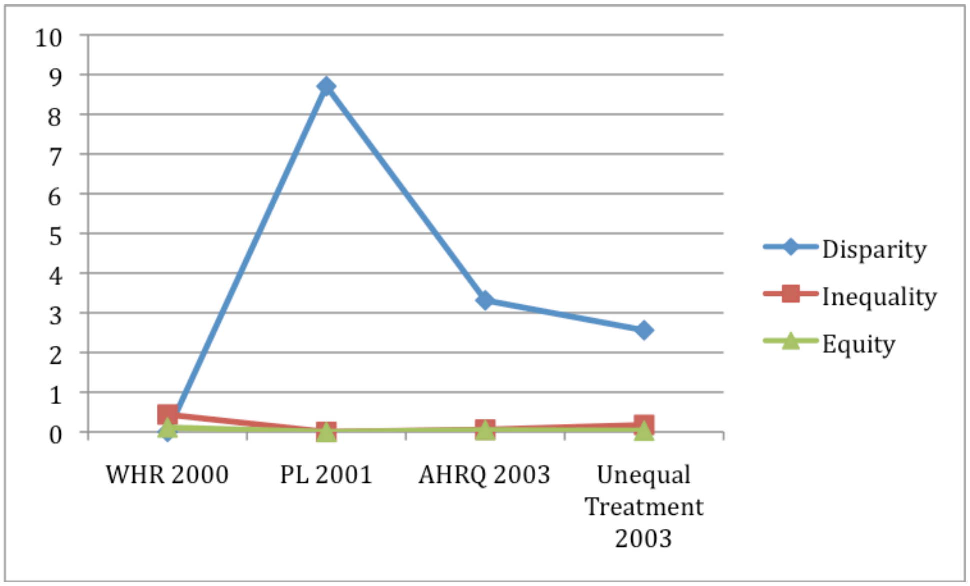
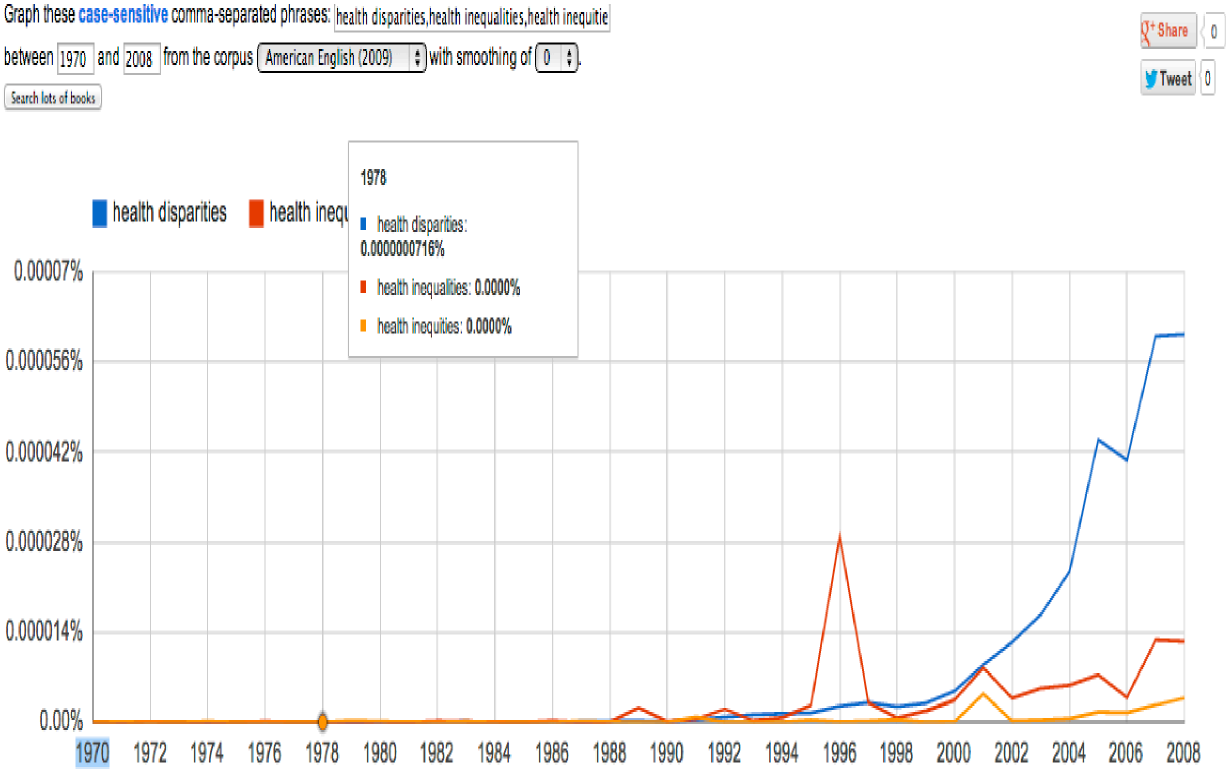


Figure 5.2: **Proportion of Words in Other Reports Analyzed**

Figure 5.2 clearly shows the dominance of the word disparity/es, peaking with the publication of PL 106-525 in 1998 and continuing in the AHRQ 2003 and in

Unequal Treatment, the IOM report. The upper line (blue) illustrates disparities, while the bottom lines (red slightly higher and green) illustrate inequalities and inequities.

I also looked at the proportional use of the words “health disparities,” “health inequalities,” and “health inequities,” in books written in English between 1900 and 2008 (the last year available for calculation). I used Google Ngram Viewer[19] to image the progression of use of the terms. I added the word health to this search to have a better chance of capturing the discourse in health. Figure 5.3 shows the results.



Graph these case-sensitive comma-separated phrases: health disparities,health inequalities,health inequitie

between 1970 and 2008 from the corpus American English (2009) with smoothing of 0.

1978

health disparities: 0.0000000716%

health inequalities: 0.0000%

health inequities: 0.0000%

Figure 5.3: **Google N-Gram Viewer, 1970-2008**

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[19] Ngram Viewer is a graphing created by Google as a tool to chart yearly counts of words. It uses over 5.2 million digitalized books and plots words found in over 40 books. I chose American English for the language. Source: “Grams Info” online.

Figure 5.3 illustrates how health inequalities (red line with the spike) and health inequities (orange line, bottom) were used minimally since 1970 with inequalities spiking in 1996; the word health disparities (blue line, taller)) appeared in 1992 and then became the dominant term from the late 1990s until 2008 (the last year available in N-Grams). The horizontal axis shows the years included in the calculation and the vertical axis shows percentage of words in the corpus of books included.

As I explained earlier, the N-Gram is a rough estimate (it is based on books, not papers, and I do not know the kinds of books, only that they used the terms in question). However, it is an interesting illustration of the remarkable raise in the use of the word disparities in the discourse related to health.

All the charts illustrate that the words and concept “health disparities” became part of the discourse in the late 1990’s both in the reports I analyzed for this study and in health – related books. The fact that a word (disparities) and a concept (health disparities) hardly ever used before 1970 in the health field came to dominate the discourse seems to be a phenomenon out of the ordinary. In effect, these numbers and charts demonstrate (although roughly) how quickly a concept can become hegemonic when government and academia disseminate it.

Conclusions

All the documents in this chapter, except the WHR 2000, embraced the limited “health disparities” definition (ignoring broader concepts like health inequalities and health equity accepted in the international discourse). As a consequence of the confines of the definition of “health disparities” Unequal

Treatment; the Minority Health and Health Disparities Research and Education Act (Public Law 106-525); and the 2003 AHRQ Report focused on health care, specifically health care disparities; emphasized individual responsibility; and did not address structural inequalities. While all the documents seemed to equate “health disparities” with health care disparities, in fact health care disparities are only a small part of health disparities in general. It is possible that they chose to focus on the one piece that appeared more manageable and amenable to regulations; however, this choice of approach was never stated, and, even less, accomplished.

In addition to findings from the qualitative analysis, I also found, through a limited quantitative content analysis, that the use of the concept “health disparities” in fact, started in the late 1990’s in official government reports and in the general discourse of books about health, and became the hegemonic term to describe the phenomenon of inequalities and inequities in health.

Chapter 6: Interview Results

Introduction

By conducting interviews with key informants, who in their roles as academics and policy makers contributed to the hegemonic social construction of “health disparities” I acquired personal perspectives on the process as it took place during the Clinton administration. As we saw in my analysis of the official reports in the previous chapter, with the exception of Healthy People 2020, there has always been reluctance to name, measure, and address structural issues that underlie the persistent gaps in health between racial, ethnic, and other disadvantaged populations. I wanted to hear directly from some of the individuals at the center of the discourse in government and/or academia to understand better the reasons behind the terms used. The reflections of the interviewees on how the definition of “health disparities” came about, and the effects of the widespread use of the terms on research and policy, added unexpected and enriching elements to the analysis.

The final sample consisted of 14 key informants (KIs). All held PhD and/or MD degrees; held high positions in the health field; are still active either in policy or academia or both. I consider them elite participants in the health field because of their positions and educational backgrounds. The interviews lasted from 30 minutes to an hour and 15 minutes. The questions probed into the definitions of “health disparities:” why the term “disparities” was chosen; whether there was a shift in language; and how the discourse affected research and policy. I coded all the interviews looking for statements pointing to the construction of “health disparities.” I grouped the interview data into 4 main themes that arose as the KIs answered the questions I posed (Interview questions available in Appendix1).

Variations in "Health Disparities" Discourse in the Late 1990s

The words don't matter; it matters that we can do something to fix the disparities (KI 015). Some KIs experienced the Clinton administration's sense of urgency, in the second term, to put in place some structures and initiatives related to health in view of the failure of health reform. For example, one KI observed that the administration was shifting strategy in order to recoup some lost ground:

> And part of what you're seeing in the "health disparities" piece, …as it plays out in the second term of the Clinton administration, is that shift in strategy politically within the administration... and you see the rise of the "health disparities" rhetoric" KI 007).

In this view, the disparities discourse seemed to be a last-ditch effort by the administration to accomplish something in the area of health.

Related to the perception of urgency, another KI said that the language used was not important. Instead, the administration wanted to put some structures in place to be able to measure, in time, whether progress had been made: "Disparities or inequalities or whatever you want to call them" (KI 015). This KI did not seem to care what words were used. For this respondent, however, the word disparities implied a clear definition:

> There was discussion that this was more than differences. However, we needed a term that would catch that these differences were not OK, were not just, and were amenable to change. And it was felt that 'disparities' was a

> more compelling term." Even the discussion about disparities had a lot of focus on the social determinants of health. I don't think the terminology has anything to do with whether we embrace the social determinants of health or not (KI 015).

Even though this KI was not invested in the word used, disparities connoted injustice and that something could be done to change them, implying that at some earlier time disparities may not have been considered changeable. The definition also included recognition that disparities were determined by social causes.

In addition, this KI did not see the definition as confined to Blacks and Whites: "I don't think disparities were defined as a Black/White issue. We tried to spend a lot of time trying to move beyond a Black/White discussion and that was also an issue with data" (KI 015). This KI meant that there were not enough data about other minority groups, like Hispanics and Native Americans. Also, more explicitly:

> For me, it is a question of fairness but I personally tend not to use the rhetoric of either the civil rights movement or social justice movement on these things. I mean, I think there is -- legitimately you can make a civil rights case around these things, but it's just not my rhetoric for those things. For me, it's just this is being unfair" (KI 002).

This informant concluded by saying that, even though individuals may be motivated by ideals of social justice, s/he chose not to frame the issue that way because s/he felt that the arguments would be more effective by framing diversity more broadly than as a Black and White issue, or a social justice issue. In this KI's views, framing gaps in "health disparities" as a social justice issue provided a narrower definition and prevents it from getting any traction in the political arena. The respondent concluded by saying: “And I think fundamentally most of the people are sort of pragmatists. In some ways they want to get something done” (KI 002). In other words, the speaker, and others in positions of power, chose not to use the words or concept “social justice” because the term would not be politically acceptable.

Another KI, unlike the previous one, thought that disparities were defined as a Black and White issue but agreed on the lack of data for other groups:

> Well, what I would say is that most of the studies were generated while looking at differences between Blacks and Whites…and that by the late 90s, it was pretty clear that the direction of the difference was always one way. Which was always the racial minorities were getting less care, as were people who were poor and less well‑educated and so forth. On one level not nice news, on another level, now we had data.

This KI also agreed “there [were] not enough data on different groups like Latinos and Native Americans at the time” (KI 012). Apparently data on poverty and education were available.

Both KIs above worked in government and were directly involved in policy during the Clinton administration. They were working with data generated by government agencies and therefore had first hand knowledge about the kind and amount of data available.

Some KIs thought that the discourse on “eliminating disparities”; and passage of Public Law106-525 were part of the effort to put some health initiatives in place before the end of the administration. One KI, however, who worked under President

Clinton at that time stated that these efforts were also embedded in the rhetoric tied to elections, "… [and] tied to race and ethnicity, even though other work that advanced the concept was already well known:

> In the 90's there was a lot of talk about cultural competence and they saw it as convenient way to link it to the underserved... There were people aware of the income gradient relationship to health and people like Nancy Krieger talking about income and race. …So you had to see the buildup between the end of the health care reform rhetoric to the replacement of that rhetoric with a political rhetoric and strategy that moved the issues that were of interest under health care reform in the Clinton administration forward. One was this "health disparities" piece….It was a rhetorical approach that government presidencies and executive branch agencies used to move ideas forward… if this terminology caught on (KI 007).

In support of the above, one KI, who also worked within the administration, said:

> By then, there was a sense of urgency to get some things done and, since they could only provide short-term funding, sustainability was a concern. People in charge used terms like going for "low hanging fruit, low hanging fruit" like "addressing language barriers or something" to "address barriers to access to care" (K011).

This comment alludes to the urgency to get some things in place before the end of the Clinton administration that would be easy to implement, and that would not be considered controversial.

Two KIs felt that the focus on “health disparities” in the late 90’s helped dispel a myth that racial and ethnic minorities’ poorer health outcomes are naturally occurring, as in: “In the 60’s and 70’s, it was: ‘That’s just the way it is” (KI 005). Or, as another KI said: “We've made enough progress in some areas to know that it's not the law of God that it has to be this way” (K012). These statements show that even in the late 90’s there was a notion that racial and ethnic minorities were somehow intrinsically more susceptible to disease, and new data were showing that poorer health outcomes among these populations had to do with external determinants that could be remedied.

Disparities only in health care, not in health in general. Another issue brought up by several KIs referred to how disparities were mostly looked at in terms of health care, as opposed to a broader definition of health: “We weren't looking at disparities in health overall, but rather health care.” The data collected from the late 1990’s about disparities in health care were important, according to this KI, because:

> As a physician, you know, I would say that when I was training in the 1980s, that most people believed racial disparities – and this is hardly news, right – but I think they believed that they all occurred outside the health care system” Right? Once people believed we treated everybody the same. And here we are generating more and more evidence[20] and studies saying, "Not really" (KI 012).

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[20] Here “evidence” refers to findings reported in the Institute of Medicine’s report “Unequal Treatment” and by research documenting ““health disparities”” recently generated as a result of PL 106-525, both of which I analyzed in Chapter 4.

These statements confirmed findings from “Unequal Treatment” – the IOM report – about health care providers’ reluctance to admit differential treatment of Blacks and other ethnic populations.

Another KI asserted that disparities in the United States in the late 1990’s were about Blacks and Whites and that they implied injustice:

> [I thought] it was a step up to at least put differences on the agenda. And initially I think a lot of people just assumed that – they just assumed it was obvious and they, from the beginning here [in the United States], they were just thinking about racial and ethnic disparities. That was really what was driving that here in terms of a movement. And I think for a lot of people, they just thought it was obvious that that represented injustice” (KI 001).

Here we hear that, in the United States disparities meant racial and ethnic, at least initially, and that the term included the notion that the disparities were unjust. This same KI continued with:

> I think David Satcher[21] – you know, he's a very smart man, and he's very astute politically, and I also think he's somebody who cares passionately about social justice. But he made a decision – and others who were in positions of power at the time made a decision – to focus on disparities in health care and not to focus – not to spend a lot of time focusing on the broader issues” (KI001).

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[21] David Satcher was the Assistant Secretary of DHHS and the Surgeon General during the Clinton administration and became the public face of the “eliminating “health disparities”” movement in the Clinton administration.

In addition to stating that everybody assumed that disparities represented injustice, this KI appeared to imply that the decision to use the term disparities was politically astute, and that it was purposely omitting broader issues and social determinants of health.

Several others echoed the idea that the term “disparities” may have been strategic. For example, in the following statement:

> I think labeling it as health disparity and then saying we must eliminate it as a nation, I thought was an excellent place to start in the '90s... I think for the time, for the social time, it was absolutely perfect…. I don't think they could have said it was inequitable back then…. because of the political climate. Now I think we can (KI 005) EBJ.

Disparities as a good way to start was mentioned by several KIs, because other words like equity, which would describe the problem more accurately, were not allowed by the political climate. Here there is an implication that the decision to use “disparities” was the best that could have been done at the time.

The previous sentiment was, in a different way, echoed by another KI who stated:

> ‘Equity’ was on the map, and it was felt that the term would turn people off, it would point fingers and label some people as “bad people” on the policy side. ‘Inequities’ was politically loaded. The goal was not to preach to the converted but to bring along people who were not knowledgeable, who were skeptical. So part of the reason for the term [disparities] was for the skeptics (KI015).

In this scenario, it appeared that, since the idea was not to preach to the converted, those who wanted to “get something done” did not fully inform “the skeptics” who were, strategically, left thinking their definition of disparities without substance was fine. In other words, the term equity would imply responsibility and those who felt responsible might have felt threatened, therefore the KI did not use the term “inequities” and used the watered down term “disparities” to accommodate them. In this process, however, those people who were not “knowledgeable,” or who were ideologically opposed to equality and equity were not given the full information.

The idea that the term disparity was less threatening was also mentioned by another KI:

> Disparity was a less threatening word than inequity. And I think people accepted it when they saw the data and said, yeah, there's something wrong. There is a disparity in the data. And they didn't have to say anybody was guilty for that; whereas when you start talking about inequity, somebody is guilty, somebody is being inequitable. And I don't think the majority was prepared to hear that until very recently (KI 005).

In the above statement, the KI felt that the term disparity allows policy-makers to focus on describing the problem without having to think back to or mention the causes. The last sentence refers to recent changes in discourse – as exemplified in Healthy People 2020 – with equity as a central concept.

For the above and other KIs, it was clear that the term “disparities” was strategic, and they felt that it needed to be in order to call attention to the issue and get something done, and that even the less controversial term “disparities” was still difficult to mention. When I asked if the term “disparity” was a strategic choice, one answer was:

> I don't know about the choice part of this, but I do know that there was a lot of work in the nation to accept the fact that there are disparities. That was hard. Doctors, especially, didn't – they rejected that concept for years – …and only recently after this Institute of Medicine report [Unequal Treatment] did the medical community begin to say, yeah, this must be real because prior to that, doctors absolutely denied it” (KI 005).

Again, we hear that the emphasis on documenting disparities in medical care was important because without hard data the medical community did not want to believe that their treatment of patients of color was different from their treatment of White patients.

A different but related perspective included the belief that, even though the disparities discourse was limited, it also was instrumental in helping scholars think about addressing them:

> It made the possibility for the national policy world to start embracing, “let's look at causes behind causes.” So even though disparities [was] the value neutral word it still allowed policymakers to then say, you know, we have to address these disparities. So, to me, it was a huge shift when disparities came in, even though I felt it stopped way short…. it allowed for there to be much more of a recognition of social determinants and structure within academia and maybe even in policy…it was an opening, even if our dominant

> hegemony is still individual, pull yourself up by your bootstraps – and we're never going to get away from that (KI 008).

Here we have a statement somewhat contradictory. It states that, in spite of the hegemonic concept of personal responsibility, the term disparities helped policy-makers look at the causes behind them. This assertion also belies the fact that inequalities in health emerged many years earlier and were not a new finding.

In reference to inequality, one KI thought that this was a concept that was used before, particularly in economics where the discourse has included income inequalities, and that disparities was a step up:

> I think it [the discourse] started out with inequality – or inequality from the perspective of the equal opportunity equality and the mythology of living in a democracy where everybody has equality of opportunity. And never was – we never had the discourse around inequity, which to me is a completely different phenomenon…So for economics, I think there was always income inequalities…..I always think of the U.S. as operating within an inequality frame… You know, that we're born maybe with differences but individually we can have opportunity to make up for that or whatever. So that's never shifted… I mean, we live in the neoliberal hegemony of that throughout (KI 008).

The above KI thought that, in the discourse, the concept of inequality appeared before disparities. Upon checking previous work during the course of the interview, however, this KI found that, in the late 1980s several scholars, including the speaker, did not even use the word "disparities," but used "'variations" instead. This

KI was surprised that s/he had not used “disparities” and explained the reason being neoliberal hegemonic thinking that permeates society.

Other KIs also said that the definition of “disparities” omitted social causes, narrowing interventions to individual level behavioral changes. For example:

> When you look at disparities, instead of looking at poverty and economic inequality and unfairness in educational opportunities and outcomes and in labor policies and structural inequities, it narrowed it back down to a big focus on prevention and behavioral health (KI 006).

In this KI’s view, the definition of “disparities” did not include root causes and resulted in a focus on prevention that only addressed individual behaviors. This view, however, is different from others who assumed that disparities included structural causes and assumed that everybody knew that disparities were associated with the social determinants of health mentioned above. For example,

> The disparity discourse was also considered a different kind of shift:
>
> It goes from being simply a difference seen by race to racial disparities. As particularly true when additional groups begin to be brought on and compared….That's the difference, that shift between recognizing the difference existed and having a name for that difference.” (KI 007).

In the above, the shift is not from equity or equality to disparities but from difference to disparity, and it is seen as a positive phenomenon.

Another KI mentioned studies such as the Whitehall study of British civil servants, where Sir Michael Marmot and colleague found “a steep inverse association between social class, as assessed by grade of employment, and mortality from a wide range of diseases" (Marmot, Stanfeld, Pate et al., 1978). However, in the United States researchers focused on providing services instead of finding causes:

> The issue of the social [determinants of health], I think it wasn't addressed as broadly as the question of disparities…I think that there were a whole bunch of people putting their brains in the use of services and lack of sufficient outreach to populations for services. It wasn't about social environment, the economic environment, or the physical environment… But we certainly knew that this was an issue because there are plenty of studies. Particularly I think in the U.S. we are aware of the Whitehall study that Michael Marmot was doing in England (KI 004).

In addition to the focus on services, health was decontextualized from its determinants.

Not in our backyard. Most of the KIs were aware of the differences between the discourse in the United States and in other parts of the world. Some had worked for the World Health Organization, and some were aware of studies by scholars in other countries. While acknowledging the wider spectrum of the international discourse, some accepted that the discourse in the United States was limited. These researchers went along with the tacit omission of social causes and issues of social justice when in the United States, while others used the broader concepts in their scholarship and in their work knowing that they were going against the grain.

As an explanation for the difference in discourse between the United States and other countries, on KI stated:

> The thing that really strikes me is that when I visit my colleagues in Canada, they really pay attention to this. They say what's hurting one group is hurting all of us as a country. It's a very different mentality. And the United States, I think our origins were that “everybody is equal.” Everybody has the same chance. No groups are better or worse. It's almost like the whole country began with that kind of focus. It's almost part of the national identity (KI 010).

This KI felt that in countries like Canada solidarity and equality of outcomes for everyone were important values while the United States valued equality of opportunity.

This same KI talked about an experience in Holland, where the academic community could not accept that a population of immigrants in their country was responsible for poor health outcomes in the city where they lived, because:

> We don't talk about those things here. In Holland, everyone is equal. We're not like you in America with all your divisions. We're one country, and we all help one another, and we don't talk about these things: Those people versus those people.

This KI also mentioned Brazil where, in spite of having a very high index of inequality “they've always had the view that everyone is equal. There's no discrimination [meant satirically] in Brazil.” The lesson here for this KI was: “This is a delicate subject, apparently” in other advanced countries as well as in the US (KI 010). This KI wanted to emphasize that the United States is not the only place where academics don’t want to talk about ethnic and racial inequalities and inequities, as exemplified by his experience.

Another KI talked about what UK researchers think of the discourse in the United States:

> I think the people in the UK and the EU saw our use of “health disparities” and “minority health,” which are sort of classified together in the legislation and in the National Institute of Minority Health and Health Disparities” (NIMHD), the institute – and in a way that health inequalities and inequities were huge, it tended to marginalize it and was viewed by the – say in the UK, for example, the descending line of strength of the language about this field of work (KI 006).

The above statement implied that the language of disparities, which associated them with minorities and ignored inequalities and inequities, weakened the work in the field inequalities and inequities in health.

Not only was the discourse in Europe different, but also it had been so for a long time. One KI traced the European discourse on disparities and inequities to the 1980s: “The European Health for All Commission developed 26 indicators, and they always had inequity or disparities in there decades before we did… certainly decades before 2000, maybe even into the 80s (KI 008).” When I asked this KI – who has worked extensively in universities in other countries and has not been directly involved in government work – why inequities did not appear in discourse in the United States, I received the following answer:

> Because I think academics [are] caught in the same hegemonic discourse of the ideology that we're supposed to be players rather than challenging or confronters. We're supposed to be contributing to discourse rather than

> saying the discourse is completely flawed or whatever. It's just that – I mean, there are few people, as we know, who will challenge. But we're supposed to sort of incrementally contribute to a slight shift of discourse versus say, there is a massive difference between how they're talking about it in Europe and how [we] are talking – The whole world has shifted and we have never changed our language in terms of health interventions (KI 008).

This response was unique among KIs, and I think that the experience of working in other countries gave this person the opportunity and insight to notice the hegemonic discourse in the United States.

Knowledge Lost and Found

While some KIs thought that the "health disparities" language in the late 1990s appeared new and an comprised an improvement that brought attention to the issue, others argued that there was nothing new about the concept and that the United States simply had not made improvements because of the narrowness of the concept. Some remembered the disparities word used much earlier, not just to denote racial and ethnic gaps in health, but also related to socio-economic issues. For instance, another respondent (KI 002) said: "In my memory, the 1960s/ '70s literature showed a lot of disparities on health care [for racial minorities and for poor people]. I don't think there was much on health at the time, but on health care." This

KI believed that some research showed that with the advent of Medicare and Medicaid, things were getting better in comparison to before the 60s[22]:

> There was a discussion around the civil rights movement and everything about disparities in all kinds of aspects, but health was there. And then, you know, people sort of expected Medicare, Medicaid to help out, and some other programs to help out…. And then I think there was a time period -- you know, my sort of take on it, there was a time period when this wasn't discussed much anymore. I think people assumed [because] you've got health insurance, everything is going to be taken care of (KI 003).

This KI remembered how after some progress in addressing "health disparities" through safety net programs such as Medicaid and Medicare, the issue seemed to have been forgotten for a while thereafter.

Another KI gave an example to show that health inequalities discourse existed before and that scholars were aware that they were more than disparities:

> In 1999 [there was] a conference called "Income, Socioeconomic Status and Health" to look at health inequalities. And at that time, Robert Wood Johnson …didn't want to support it. I mean, they thought that was a little far out. And neither did Academy Health … we were aware that looking at health inequalities and income inequalities was a sensitive issue, but there was a fair amount of support for it within certain parts of HHS (KI 006).

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[22] The KI referred to this paper: Davis, K. and Reynolds, R. (1976). The impact of Medicare and Medicaid on access to medical care. In *The Role of Health Insurance in the Health Services Sector* by Richard N. Rosset. National Bureau of Economic Research) 391-436).

The above statement illustrates that even in the United States there was counter-hegemonic discourse and work that was resisted by the mainstream. There were also, according to this KI, several books published in the US about the influence of income inequalities in health.[23]

One KI gave a brief history (KI 004) to highlight that knowledge about the social determinants of health goes back to Greek times and continued throughout the centuries. In spite of a myriad of studies from other countries and, many in the United States, in the 1990's and earlier, discourse about the social determinants of health did not enter the mainstream in the United States.

Yet another KI saw a different change in the meaning of disparities, from mere differences, to then being conflated with inequalities, but still not concerned with equity:

> "Health disparities" and health inequalities – not health inequities – towards … the middle of 2000 to 2003, became interchangeable. They didn't really maintain the conceptual purity of only being differences, which is clearly what people were talking about in "health disparities" within the executive branch, without making a judgment about the equitability or inequitability of those differences. And those who were, in fact, more interested in looking at the inequity that underlies those disparities, that nuance to understanding wasn't

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[23] Scholars in the US, mostly in public health who recognized the importance of social determinants like race, class and social conditions in health and wrote about the subject in the 90's and early 2000's mentioned by this KI: Paula Braveman, Nancy Krieger, John Lynch, Ichiro Kawachi and David Williams, among others.

> really part – at least in my interactions with people – was not part of the discourse (KI 007).

Here we hear that the executive branch was talking about disparities as differences only, the academic community was talking about inequalities, and those interested in talking about equity were not part of the discourse. Clearly, the definition from the executive branch prevailed.

Another KI talked about how work about health inequalities and equity was considered scary and dangerous:

> Because people were feeling, oh, my God, it's so scary talking about health inequalities and equity and social determinants of health. That's socialism. Socialism does not work in this country…. And at the same time, the American Enterprise Foundation[24] was attacking all that body of work. Charles Murray wrote a book on income and equality and IQ in 1998[25] arguing that inequality and income and health were really things done differently due to IQ and differences in effort (KI 006).

This statement brings home some of the reasons why the ideas of social determinants and equity in health have not taken traction in the United States. On the one hand, people are afraid of anything that may be considered “socialist,” perhaps based on a surface understanding of what the concept means; on the other,

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[24] The American Enterprise Institute prides itself on producing leading research in several key policy areas that weave a tapestry of the organization's core beliefs: respect and support for the power of free enterprise, a strong defense centered on smart international relations, and opportunity for all to achieve the American dream. Source: http://www.aei.org/policy

[25] Refers to: Murray, C. & Hermstein, R.J. (1994). *The Bell Curve*. New York: Free Press.

there is strong and well-funded opposition from conservative and neoconservative institutions such as think tanks that oppose many initiatives.[26]

A narrow definition leads to narrow initiatives and does not lead to elimination of health disparities. When asked if the “health disparities” definition had an effect on eliminating them KIs expressed different opinions. For instance:

> If you're trying to treat the symptoms, you're not really getting at the disease. And unfortunately, our focus on the symptoms is what “health disparities” is about: outcomes, rather than looking at the underlying social disease that is leading to those differences (KI 007).

Another KI agreed “At the end of the day, you really can’t change health outcomes without addressing social determinants” (KI 015).

In the above statements, we hear that focusing on “health disparities” only addresses symptoms and neglects underlying causes – the social determinants of health – and that without addressing the causes, there is no progress in eliminating or even reducing disparities.

Others felt that the lack of progress in reducing “health disparities” was due more to the complexity of the issues, which requires involvement of sectors other than health. This complexity was not addressed in the 1990’s or thereafter. However, some KIs felt that discussions between sectors are beginning to happen now (in 2012), as in:

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[26] For an analysis of the influence of think tanks on policy see: www.psmag.com/politics/think-tanks-are-nonpartisan-think-agai-39850/ and, Rich, A. (2004). *Think Tanks, Public Policy, and the Politics of Expertise*. Cambridge: University Press.

> Well, I think part of it [failure to eliminate “health disparities”], you know, is because we're dealing with very complex issues... And so this is not something that can be addressed just through the health sector, and [I think] what’s happening is encouraging. From what I hear from the Department of Health and Human Services…they have a regular meeting that's occurring between the Office of Minority Health and each of the other departments. In other words, education is at the table; housing is at the table; EPA is at the table. They're all at the table talking about what they're doing to address “health disparities” (KI 011).

The above KI is seeing signs of improvement at high levels of government. The next KI agreed:

> I think the way that we frame the issues now hopefully has opened up thinking about new policies and strategies. I think for example, the interest in place/space initiatives to address neighborhood conditions that shape health [has promise] (KI 003).

These KIs see a difference in how issues are being framed now, such as addressing social conditions like “place” and acknowledging the need to look at root causes. This new frame requires that different sectors of government work together.

In the above perspectives, government agencies appear to be cooperating and acknowledging the need to address health inequities with comprehensive strategies. As another KI, however, explained, there is an element of doubt as to whether a new equity frame will prove effective because of the complication presented by current economic conditions:

> I think it's too early to know if this shift in language and framing has made a difference in terms of improving health status and eliminating health inequities. But that's going to be a tricky question to measure because...it’s very, very difficult to isolate the effects of particular interventions in the health equity arena when we know so many are influenced by broader social, economic, and political forces. For example, the economic downturn over the last few years has probably made health inequities worse (KI 003).

This KI expresses a concern that, even with a new equity frame, there may not be any gains, or, if there are, it will be difficult to ascribe them to the new frame.

Other KIs (academics), who also worked with communities, expressed different perspectives and stated that they did not engage much with the dominant “health disparities”” discourse, as we see in the following:

> We may not have called it inequities, but there was a sense of health equity and that there were social determinants of health such as poverty, poor education, and that they needed to be addressed as systemic issues [in the communities] (KI 009).

Even though this KI and the people in the community did not use the word “inequities,” they applied the concept in their work by addressing their underlying causes.

I heard another example of this kind of thinking from a different KI:

> I'm afraid I was always thinking about the social determinants of health…. Because I think what has really helped is I've been involved in the last ten years – and I was probably one of the first people in the United States to work

> on health impact assessments, and that was because it was clear to me that the major determinants of health were in other sectors. So I've been doing that for over a decade now… because of my belief that it was these broader issues, some of the physical environments and some of the social environment. And … I felt this was absolutely essential to our understanding of what needed to be done to improve health. So for me, this is – you know, I've always been a little bit ahead. And the other is health in all policies, which is something that, you know, evolved during the first part of the year 2000. I think that was just another way of expressing the same thing: that we had to look at everything we did from a health policy place and try and figure out how it could support improved health and improved health equity (KI 004).

For the above KIs, involvement in communities brought them to a fuller understanding of social conditions and to make efforts to address them effectively. The second KI also has been involved in the development of Healthy People 2020, where his team accomplished openly addressing the social determinants of health.

Fear

The theme of fear came up in several of the responses, expressed in different ways. The KI's shared stories of fear -- their own or others – and of anticipated negative consequences such as losing a job; of raising negative opposition; and negative reactions from respected colleagues.

Fear of losing one's job: Alteration of the report from the 2003 report by the Agency for Healthcare and Research and Quality (U.S. DHHS AHRQ, 2003). According to a KI, staffers who altered the AHRQ report were afraid of losing their job security. This KI, who was working within the administration at the time, and witnessed the events, said:

> Another reflection is that people were scared. They were really scared of losing their jobs, and so they were so scared that they were anticipating what the administration would expect them to do. They wouldn't even bother asking, okay? They were just anticipating. And that's what happened with that AHRQ report. The person who made that decision as to what could be reported in that AHRQ report that you hear all the hula about was a career person. He wasn't a political person; he was a career person who had been through previous administrations with Democrats and Republicans before, but was so scared to death of losing his job, you know, that he would – he anticipated what the administration would want to see…. In career officials, courage is lacking (KI 011).

This KI felt that career people, because of their fear [of losing their jobs], and in spite of their personal beliefs, didn't even bother to ask, but anticipated negative reactions and personal repercussions. When they deemed that an issue might upset their boss, they avoided it "because it was considered too controversial for the administration" (KI 011). According to this KI fear functioned here to prevent high level government functionaries from acting according to their conscience and pre-empted common sense.

Another KI expressed a similar opinion about the reasons for altering the report, although in a softer language than the previous KI: "Some over energetic political staff thought that in some way this report would make them look bad. So they toned down the language” (KI 012). Here the KI did not mention the deletion of important findings. This same KI added:

> [There were] many fights about this, and then someone leaked the original report. I believe it was an HHS employee. I have no confirmation of that, by the way. So in essence, what the Bush administration managed to do was to take old news and make it a controversy. I mean, it's not as if disparities started after President Bush was elected (KI 012).

The KI implied that, had the alteration of the report remained within the walls of the agencies, the administration would not have felt obligated to release the original. Furthermore, this KI felt that there was no controversy about racial and ethnic disparities because it was not a new finding. However, this same KI also added about those who wanted to alter the report: “These people didn't have that kind of breadth of knowledge or perspective or good intentions to understand that the roots are deep” (KI 012). In this case, in addition to fear, this KI stated that intentions of the staffers were also questionable.

Fear of organized opposition. One KI expressed that there was organized opposition from both within and outside of government and described the opponents: “Look at what is happening now. It’s people in our country afraid of change. People who are uneducated - and it’s frankly a consequence of an educational system - that reinforces racism and bigotry” (KI 015). In this statement we hear that people’s fear of change and inability to assess whether what they hear is reasonable, stokes their racist beliefs, and allows them to accept hegemonic views.

Fear of negative reactions and disapproval from colleagues. One KI told me an episode of intimidation early in a long academic career:

> In 1961 I presented my first paper. It was about social factors in heart disease. One of the most famous epidemiologists in the country [told me] never to talk about such things again. I backed off. And I said, you know, I'm not so much interested in proving my own theories. I'm really more interested in making a difference, so that I almost felt that when I talk about the things I really care about and to hell with the response, I thought that was self-indulgent, that that would just make me feel good, but it wasn't going to change anything. So I really backed off. I began to talk much more gently, much more subtly, trying to influence a whole generation of students and try to make the world a better place, but in a very gentle way (KI 010).

In this story, the KI construed "backing off" as: "toning down my rhetoric in the interests of really making a difference," and deciding, from then on, to avoid speaking in terms that could be considered inflammatory.

Years later this KI had an experience where someone pointed out the avoidance of "real issues:"

> One day I was giving a talk… and this guy got up in the audience and said… You're talking all these words but what you're really talking about is power. Why don't you just come out and say that…[and] I said, I learned long ago that when I talked about things like that, bad things happened and I was not being heard at all. And I made the decision to tone down my rhetoric in the interests of really making a difference… I don't really need to do that

> anymore…but … once you learn a certain way of dealing with things, you tend to keep doing it, even though it's no longer appropriate or necessary. For God's sake, [at my age] I should be able to say whatever is on my mind. But I don't… I haven't really adapted to that. I'm still trying to be gentle. I've always been very cautious, even though I really don't need to be anymore. I think I really am committed to making a difference. I care about that more than anything (KI 010).

This story is about fear instigated by a person in power early on, and a personal decision to not be exposed to that kind of reaction again. This KI made the choice "to be gentle" and believed that this strategy increased effectiveness.

Effects of Passage of Law 106-525: "Minority Health and "Health Disparities" Research and Education Act of 2000"

This law was important because it mandated the National Institutes of Health to conduct research on "health disparities" at the national level, and it was an effort to elevate the issue.

The KIs who spoke about the law agreed that, unless measures are taken to address the social determinants of health, progress in eliminating "health disparities" would not happen. Therefore, since "health disparities" were defined in narrow terms, and Public Law 106-525 was based on the same definition when it mandated research, it is no surprise that there has been no reduction in "health disparities" since enactment of the law in 2000:

> The outcomes are worsening all the time because not only [in] our society but in almost every country, unless they're taking specific efforts to reduce

> economic inequalities, they're not making progress on health equality. It's like 90 percent of the research over the last ten years has been on describing the problem and the magnitude of the problem, and only recently has there been more concerted effort to act and to change policy to make a difference (KI 006).

The above KI felt that the law did not help because of how it defined disparities. Another KI, however, also felt that some of the blame for the descriptive research is due to academic constrictions: “It is easier to count than it is to work with systems and communities to change it” (KI 015). Counting, in this statement, means describing disparities, which is what the majority of researchers did after passage of the law.

Other KIs agreed that much of the research conducted and published after passage of law 106-525 in 1999 was focused on documenting and describing “health disparities,” and had different opinions as to why:

> I think that the disparities research has been really cookie cutter research, not really risky or creative or wanting to make change. This has to do with academic reward systems that support people publishing lots of papers instead of trying to change anything. And I think that kind of research continued to just prove that disparities existed instead of putting the energy and requirements on what to do about them (KI 015).

This KI felt that the majority of research on health “disparities” ended up being descriptive due to the academic culture. A different perspective, however, linked the research to the rhetoric:

> Because of this increased focus and rhetoric around “health disparities,” you'll see increased academic production of people trying to explain their analytic work, particularly around race and ethnicity in the context of the political rhetoric of racial and ethnic disparities. Most of the work end[ed] up being descriptive for almost 20 years or more [after 2000] (KI 007).

In this KI’s view, the discourse directly influenced the research focus.

Still, another KI felt that the definition of disparities opened an opportunity for minority researchers to highlight the disparities in a way that had not been possible before:

> I think agreeing with the label created a whole niche for young researchers to work in that area. It became acceptable in the academic institution. It was not acceptable when I was a young faculty member. People didn't even talk about disparity back then….Back then in the ‘60s and the '70s, it was just "that's the way it is" (KI 005).

In the above statement, the KI compared the climate of the late 1990’s to 30 years earlier and posited that the disparities discourse allowed minority researchers to delve into disparities research.

In addition to the research being descriptive, a KI thought that PL 106-525 not only resulted in a great increase of descriptive research but also influenced how to measure and use race in research:

> You ended up getting “health disparities” identified as a research issue, whether it was under the Centers for Disease Control (CDC) or whether it was Health Resources and Services Administration (HRSA) or Substance Abuse

> and Mental Health Services Admini0stration (SAMHSA), or any of the executive branch agencies…. But it also was at a time in which the concept of how one measures and collects data on race and ethnicity was at the forefront of review. …. And that had a severe implication for academic research. The academic community increasingly simply accepted the conceptual measurement of race and ethnicity as if it had some coherent theoretical or other underpinnings, and often did not challenge the use of those variables in their own model or statistical modeling such that race and ethnicity now become variables that pick up whatever is left over in variation or muddy and confound the interpretation of other variables in modeling. So this whole push has really led, to some degree, to a distortion…of scientific investigation. But it's propagated the use of race and ethnicity as a conceptual term that's worthy of looking at without challenging the underpinnings of the concept itself. So when results arise out of those differences, out of that variable, it feeds into this concept of “health disparities” as racial ethnic “health disparities” (KI 007).

The above assertion was not mentioned by any other KIs and it has implications for “health disparities” being understood as a racial and ethnic problem, which brings another dimension to the “health disparities” discourse. At issue is how researchers may have ascribed “health disparities” to race and ethnicity without strong scientific base.

On the importance of the law’s mandate to increase research, several opinions emerged. The first illustrates that the data were needed and did not question the kind of data:

> Well, there was a desperate need for data and better research and that was always part of the discussion. There was awareness that there were structural issues, but the policy on research was very critical. The data helped to bring attention to the issue and people begun to realize that there were great disparities in health and education for minorities. I think that the CDC started to develop programs and get an action plan together with a focus on services and research. Allocating money for research was very important to raise awareness about the health conditions of minorities (KI 009).

The second opinion was that the funding generated from the law was insufficient[27] and as such, it did not help to expand its reach or conceptual framework:

> Do you know when the National Center of Minority Health and “health disparities” was created in 1999? So they started a center with little money, little credit, little credibility, and little status. It took them until last year to [elevate it to] an Institute… So … when you're a center in the NIH world, it's not very high status. A center and an office [the office was created in 1986] are not the same as an official institute. And there are 27 institutes now, maybe 28 – I don't know – where institutes get much more of a straightforward funding stream with high-status research dollars ….But it only

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[27] The Institute of Medicine published a report analyzing PL 106-525 (IOM, 2006) that stated that PL 106-525 authorized $100 million for research but that, even though the funding was approved, it was never allocated, which made the law an unfunded mandate.

> happened last year. So from 1999 to 2012 they've been a center with limited monies. So they didn't even get the status. But they're using “health disparities” for racial, ethnic minorities still predominantly. [It is still about] “Let's just get competent in how you eat and then we can know how to work with you. As long as we know what you eat” (KI 008).

This KI was remembering the history of the issue of disparities and the attention it received in government. In 1985, after Margaret Heckler’s report[28] an office was created, and research was mandated. Then, in 1999, the office was elevated to a National Center on Minority Health and “health disparities,” and more research was mandated. More recently, in 2010, an Institute was created.[29]

Pondering about the effect of the public law in 1999, which was touted as a major piece of legislation, one KI also felt that it did not provide for enough funding: “It's very modest funding. It's really – it's just a beginning. To me, it's more symbolic, [even now that they] have an institute. The funding is still really not appropriate” (KI 010). And also this KI thought that, even after the creation of the Institute, the funding was still inadequate, and, more importantly, that the process was more symbolic than substantial.

Another perspective, adding to the above concerns, explained the effect of funding on academic research in a different way:

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[28] Report of the Secretary’s Task Force on Black and Minority Health, Vol 1: Executive Summary. US Department of Health and Human Services, DHHS publication No. (0-487-637), Government Printing Office, 1985.

[29] It should be noted that the announcement of the Institute was part of the Patient Protection and Affordable Care Act (P.L. 111-148), March 23, 2010.The Act included a definition of disparities as: “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups” Source: http://www.nimhd.nih.gov/.

> The academic research agenda is always dictated to a large degree by where the money is placed and how the money is described. And if the money is described in a political rhetoric, then academic researchers … have to create research projects around the rhetoric of those RFPs and pursue those dollars, because if they don't, then they're out of a job (KI 008).

The statement above illustrates how the political definition of a concept dictates where funding goes, which in turn influences the kinds of projects researchers pursue.

Most KI’s agreed on the limited effects PL 106-525 had in helping to elucidate the causes of and remedies for “health disparities:” however, their opinions as to why varied considerably: from blaming the narrow definition and rhetoric about “health disparities” for the law’s limited reach; to blaming academia for rewarding “easy,” “cookie cutter,” and “not courageous” research, as opposed to most difficult investigations to find causes of and remedies for disparities. Others felt that the NIH funding priorities encouraged researchers to pursue descriptive research because they knew it would be funded; in doing so, they accepted the NIH’s and the Law’s definition of ““health disparities”” (following the money).

On Race and Class

Data on class are not sufficient. KI’s had different opinions about data on class. For example:

> David Williams … shifted the discourse around race and class. Well, the other piece of why the U.S. is different in terms of looking at racial disparities as a

> bottom line is because we don't have a way to, as a society, collect social class data consistently (KI 008).

It has been pointed out that it is very difficult to have enough data on income because many people don’t report their income, and because, unlike in other countries, we do not collect data on occupational categories. However, one of the KIs who worked in government for several decades was emphatic about the existence of the data:

> The data have been presented. They have been collected. That's not the reason why we haven't been acting as we could or we should… It's not for lack of data. We have the data. There is a big difference between collecting the data, analyzing the data, and disseminating the data, okay? And we've run into that problem with Healthy People that the data were collected, but they weren't analyzed. If you look at Healthy People, the way it was presented, they have this category called DNA, which is Data Not Analyzed. … In some cases they were analyzed but they weren't disseminated (KI 011).

While several KIs stated that more data were needed to adequately measure poverty, the above KI contradicted that belief.

Class is not talked about much in the United States. Informants had different opinions on why race is addressed much more often than class and why. One KI stated:

> In the United States, just as it is when we were talking about race, we don't want to talk about class. We don't want to talk about inequality and people -- certainly, those on the right -- have attempted to dismiss inequality and have

> attempted to dismiss both racial and class differences as being of the -- really, the byproduct of the inability of low income and minority groups to compete or something along those lines…. we need to better understand the intersection of race and class. Too often, however, people in the U.S. have conflated race and class so that when people are talking about people of color, low socioeconomic status is assumed, obviously, incorrectly. Among some advocates, part of the fear in the discussion around class and the focus around class disparities is that, from a policy standpoint, if government efforts are focused on both addressing racial and ethnic health inequities as well as socioeconomic inequities, then the fear has been that there would be fewer resources focused on addressing the needs of communities of color, sort of a dilution of the meager resources that we have to focus on other population groups (KI 003).

For this KI one of the reasons why class is not talked about as much as race may be fear on the part of advocates that resources are scarce already and will be diluted even more if class inequalities are addressed as well.

Other KIs agreed that race is really a proxy for class because class is difficult to talk about. One expressed that conversations about class seem more difficult in the United States, compared with Britain, for example:

> Margaret Whitehead[30] explained that her definition of health inequalities is health differences that were unfair and unjust and avoidable. You know, that had -- that was something that nobody questioned there or said, Well, how do you measure that? If there is so much acceptance of the fact -- acceptance of two things: One is the -- that what they were talking about had to do with class; and number two, that class structures are unfair. So those were the two premises, you know. And they started from that standpoint (KI 001).

In the above, the KI agreed that class is not talked about in the United States and also mentioned the connection between unfairness of class differences and equity.

As we saw in the above quotations several KIs felt that the emphasis on racial and ethnic populations in the disparities movement overshadowed and perhaps even pre-empted discussion of class. They, however, saw different reasons why class is rarely mentioned: there is a tendency to ascribe disparities to personal shortcomings, not to structural inequalities; race is used as a proxy for class; some advocates fear that scarce resources for minority health would be diluted even further if socio-economic inequalities were addressed also; and class analysis is not popular in the United States because of reluctance to admit that the existent class structure is unfair and avoidable.

Class is important but race is more so. Several studies have shown that, controlling for class still results in race as a predictor of disparities in health:

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[30] Margaret Whitehead is a renowned academic and author interested in health equity. Among other important documents, Dr. Whitehead was the author of “The Concepts and Principles of Equity and Health”, a document published by the World Health Organization in 1990.

> There is an issue of class, obviously, and some people believe that it is class, not race. But the data show that, when you control for income and education, race is still a predictor of poorer health outcomes. Obviously we need to talk about class, issues of poverty, issues of equity, racism, sexism, and how to change all these dynamics through policy. We have already seen an example of this in the women's movement, where women together made a big difference through pursuing legislative changes. They represented interest of class, sex and race (KI 009).

And,

> As you know, the Black/White health issue has been documented for a long time… I remember W E B DuBois talking about health inequalities and Martin Luther King talked about health inequalities being the cruelest of all inequalities. And even in 1985, Secretary Heckler, in a Republican administration, came out with Black/White health reports that looked at the health – the health gap between Black and White Americans. So it's been – it's been an issue. There's been a lot of evidence … because there's been enough data collected to underline that issue for a very long time (KI 006).

The above statements speak to the importance of looking at health disparities by race and that there were sufficient data (e.g. DuBois, 1899) for a long time to justify the study of disparities (the first statement) and inequalities (the second statement). However, they acknowledged that we also needed to talk about other issues that affect health.

Talking about race and class is dangerous. Most of the KIs mentioned the debate about race and class or race versus class. For example,

> I always thought that race was just proxy for being poor. Minorities are poor in this country, and the majority has the money, and I think it's just a proxy…. It’s easier to say Black people are sick or Latino people are sick than it is to say that poor people are sick. Because that's what it really is. It's just a proxy for saying that. But the majority has not been quite willing to accept that, and I also think that's why they killed Dr. Martin Luther King, Jr., because he began to fight for the poor, which included poor Whites and Blacks and Latinos and everybody. And that's when he got killed (KI 008).

This was a strong statement that implied that talking about the poor and racial and ethnic minorities as affected by the same inequalities is dangerous. This belief was echoed by another KI:

> In 1957 Hollingshead wrote a book about social class and no one paid much attention because the idea at that time was that there were no social classes in the United States…And it was only later as I began to do my work that I began to realize, you know, he was talking about one of the most important things of our time. But [at the time] that wasn't an issue…Also the idea (paraphrasing) that social factors had something to do with heart disease was not accepted [then] and cardiologists thought that it distracted people from the important things like high cholesterol levels and cigarette smoking (KI 010).

In this KI’s experience, when academics talked about class they were ignored, and it jeopardized their advancement in their fields.

The same KI also considered the “Occupy Movement” a very important development because it brought the issue of class out in the open and emphasized the unfairness of inequalities in income and wealth:

> And to me…one of the most important events of all is the Occupy Movement. It’s chaotic. They don’t have an agenda. They aren’t doing very well. But the impact of the Occupy Movement, to me, for the first time ever talks about the fact that one percent of the country has unbelievably larger inequality than the other 99 percent. And I think for the first time people really began to see that and say, you know, that’s not fair (KI 010).

The implication here is that, for the first time, a large number of people in the United States organized as a movement that recognized and spoke aloud about the unfairness of the class structure. However, this movement was quickly repressed.

Another KI connected the omission of class to the omission of the social determinants of health:

> I think the social determinants, of course, leads us right there. It leads us to poverty… but I don't know what's going to happen with it if the people with money started pulling out. But then – I don't know if we're going to do it [talk about poverty] (KI 005).

This statement explicitly exposes concern that if the issue of poverty is openly addressed, people with the money will become threatened or upset, and they will pull out the resources that are needed to alleviate poverty. This same KI implied that, since the issue is one of redistribution of resources, and the rich don’t want to hear about it, some groups like the Tea Party have risen to support their position:

> That's why the Tea Party is rising in power. It's a hate against the poor and those without resources, and that's mostly minorities. And there are a large number of Whites, too, but they sacrifice those Whites to get to the minorities. I think that's the tea party. That's the whole foundation for them...And [they are] poor, by and large. But somehow they think they're better than people of color…and they think that if they rise up that they'll get something. But they are very smart in playing us that way. The rich have always been very smart in keeping the poor people fighting each other rather than them (KI 005).

This KI expresses a theme that no other KIs mentioned: how one of the reasons why class and race issues are not addressed together has to do with a hegemonic tactic of keeping oppressed groups separate and fighting against each other instead of working towards ending inequalities and inequities. In this case, fear comes from “the rich” who want to keep the poor divided along racial lines.

The reason for reluctance to talk about poverty, according to the next KI, may be that it leads to asking questions about root causes, and this inquiry leads to structural issues that certain groups in society do not want to address:

> …There has been a push back, as there is a considerable body of researchers and policymakers and practitioners now pushing back to get the focus upstream on root causes of health inequalities. And I think it's safer to do that work now than it was ten years ago, that over the past 12 or 15 years, it was – initially, there wasn't much funding for that kind of work, and it was – people were – it was a threat to their tenure and to their reputation for them to do that kind of work. And over time, it's been, I believe, more and more

> acceptable for people to look upstream at root causes and also for people to suggest the kind of actions and the kind of policy – policy actions and programmatic interventions that would be necessary to make a difference (KI 006).

This KI has seen a change in the academic environment in favor of conducting research on systems, and sees hope that researchers are feeling less inhibited, and are able to get funding for researching structural causes.

Conclusions

Concerning the way that disparities were defined in the late 1990’s, and the effects of that definition until at least 2010, the story I was able to weave from interviews with key informants follows this line: The Clinton administration was coming to an end, health reform had failed, and the executive branch had very little time to get some things done related to health. Under this pressure, they made some strategic decisions: to concentrate on “setting up some structures so that progress in addressing “health disparities” could be measured;” to ward off “organized opposition” by watering down the rhetoric so that, instead of “preaching to the converted” they could carry the “skeptics” along with more palatable language; to focus on “low hanging fruit” – such as providing cultural sensitivity training –; to ignore scholarly research in the United States that was uncovering the importance of the social determinants of health, as well as international discourse around income inequalities and health inequity; and to omit the social determinants of health and even social class.

Thus, the Clinton administration constructed disparities as mere differences, and abandoned the issue of how they came about or who was responsible. This administration created a center to address racial and ethnic disparities, but did not fund it adequately. In addition, the administration geared research towards describing health care disparities in access to and quality of medical care. There were very little data on economic disparities in income and wealth, or, if there were, they did not get analyzed or disseminated; and subjects like government responsibility and class were not confronted for fear that they might have been considered controversial.

The strategic efforts, then, concentrated mostly on racial and ethnic disparities, access to medical care, and passing laws to increase research to document "health disparities." Public law 106-525 proposed to educate more minorities as providers, teach cultural competence to health care providers, and publish a report with the results of the research. All these initiatives were accomplished without calling attention to racism, classism, determinants of health, or government responsibility to implement structural changes that would address root causes of inequalities in health outcomes.

In the meantime, most researchers in academia, foundations, and government entities followed the Administration's mandate. They found disparities in every area of health care, in every setting, and in every population of low status. Great efforts and resources were spent to put together and publish reports such as Healthy People 2010 with the goal of eliminating "health disparities" within 10 years; the Institute of Medicine's "Unequal Treatment Report" finding inequalities in medical treatment; and the 2003 Agency for Healthcare Research and Quality's first "National Healthcare Disparities Report" documenting that, indeed, disparities were widespread and that the data warranted doing something about them.

In spite of all the efforts to slide under the radar, officials within the Bush administration felt that the term disparities could be too strong, so they tried to soften the AHRQ report. They attempted to alter it by eliminating the term "disparities" and using "differences" instead, and by highlighting successes instead of failures. However, when the original report was leaked to the media, Bush administrations officials apologized and released the original report.

Twelve to fourteen years later, the 2011 National Health Disparities Report[31] documented, as it had year after year since 2003, that "health disparities" continue to exist in quality, access, services, etc. Key informants who worked during the years in question agree, for the most part, that the lack of progress in reducing "disparities" is directly related to a definition that ignores the social determinants of health and social justice; and that is not in tune with international analysis of causes of inequalities and inequities that besiege the United States, in spite of awareness and concern about the causes and depth of the problems.

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[31] The National Healthcare Disparities Report (20110. Rockville, Maryland: US Department of Health and Human Services. Accessed at: www.ahrq.gov/qual/qrdr11.htm

Chapter 7: Discussion

The Failure of the "Elimination of Health Disparities" Project

It is now 2013. Fifteen years have passed since President Clinton and his Surgeon General David Satcher proclaimed plans to "eliminate health disparities." I just listened to both of these gentlemen talk about health disparities[32] and what to do about this intractable problem. And, yes, they talked about the social determinants of health and the need to create the conditions for good health, and they mentioned health equity. President Clinton recently started a new initiative to improve health through technology with private companies like Verizon. Dr. Satcher, at a recent lecture, focused on healthcare, diet and exercise, and leadership willing to "care enough, know enough, do enough and [be] persistent enough." Neither President Clinton, nor Dr. Satcher talked about eliminating structural inequalities that create and sustain the conditions that determine health inequalities and inequities. For example, neither of them mentioned policies or interventions to ameliorate poverty, racism, or unemployment.

In thinking about how to frame this chapter, the above information made me take pause. In spite of recent changes in health discourse as evidenced in Healthy People 2020, the major engineers of the social construction of "health disparities"

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[32] "Bill Clinton Says Foundation Will Tackle Health Disparities". Under this title, we read: President Clinton initiated a new initiative that involves private corporations. "Among them, said Dr. Peter Tippett, chief medical officer of Verizon's health information technology practice, are networks that will allow rural doctors to send X-ray images…" Accessed April 3, at: http://www.huffingtonpost.com/2012/11/13/bill-clinton-foundation_n_2121180.html.
"Former Surgeon General Offers Insights Into the Future of Ending Health Disparities," a presentation to the School of Nursing at Duke University, January 28th 2013 by Dr. David Satcher. Accessed April 3, 2013 at: "http://nursing.duke.edu/news/former-surgeon-general-offers-insights-future-ending-health-disparities." May be watched at: http://tinyurl.com/Satcher

(President Clinton and his former Surgeon General, Dr. David Satcher) continue to offer solutions that emphasize individual changes and medical care and are investing considerable financial resources to address symptoms, not root causes of health inequalities and inequities, even though they are exercising leadership positions outside of government. While it is discouraging to observe the intractability of “health disparities” and the gulf between the problem and the solutions that highly respected policy and opinion makers propose (like Clinton and Satcher), it becomes even more important to understand how hegemony’s power operates to enforce the disconnect between discourse and action.

In my study, I aimed to analyze discourse to:

- Clarify how “health disparities” were constructed.
- Unveil the underlying beliefs and values (explicit and implicit) guiding the dynamics that contributed to manufacturing reality and consent about the definition of “disparities” without an equity framework, and
- Make the links among discourse, institutions, and government (or the micro, meso and macro-levels) that resulted in the dominant social construction of “health disparities.”

I found the “health disparities” discourse, from 1979 to 2010, as exemplified in government documents I analyzed, narrowed to three main concepts: 1) The problem of health disparities resides mostly in individuals from disadvantaged racial and ethnic groups; 2) individuals who make “bad” life-style choices are responsible for their poor health outcomes and need to learn better habits; and 3) access to medical care is the most important aspect of health. Because of the narrow scope of the definition, the dominant health paradigm omits issues of justice, equality and fairness. Strategies to eliminate or even reduce health disparities, therefore, do not include systemic solutions to problems such as structural economic and racial inequalities. Consequently, inequalities persist in spite of “prevention”[33] efforts.

President Clinton announced his initiative to eliminate “health disparities,” in 1998. Since 2003 the Department of Health and Human Services (DHHS), through the Agency of Healthcare Research and Quality (AHRQ), has published the National Healthcare Disparities report yearly. These reports clearly document no improvements in “health disparities” in the years up to 2011, in spite of healthcare being the focus of many debates, reports, research and interventions.

Tables 7.1 and 7.2, which show the AHRQ’s main findings in 2003 and 2011, demonstrate that there were no important changes in inequalities in eight years in spite of focused research and data collection. For example, data were still not sufficient on minority populations other than Black. Insufficient data in 2011 referred to data on certain minority populations, or the lack of “a single national healthcare database [that] collects a comprehensive set of data elements that can produce national and State estimates for all populations subgroups each year” (AHRQ 2011, 1). The data may be old, or not consistently collected every year. One may ask why data problems persist, considering that they were identified in 2003 and every year since then, and why the problem of disparities appears intractable. It should be noted that tables 7.1 and 7.2 do not illustrate disparities in health in general, but

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[33] Policies in the period under study, particularly from 1990 to 2010, focused their prevention efforts on changing the way individuals in racial, ethnic and other vulnerable populations behave.

instead focus on healthcare. However, there have been no substantial improvements in unequal care either.

Table 7.1: Findings in AHRQ National Healthcare Disparities Report 2003

• Inequality in quality persists.
• Disparities come at a personal and societal price.
• Differential access may lead to disparities in quality.
• Opportunities to provide preventive care are frequently missed.
• Knowledge of why disparities exist is limited.
• Improvement is possible.
• Data limitations hinder targeted improvement efforts.

Source: U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality Rockville, Maryland, 2003.

The table above highlights the main findings in 2003. The table below highlights the main findings in 2011, eight years and eight reports later.

Table 7.2: ***Findings in AHRQ National Healthcare Disparities Report 2011***

• Healthcare quality and access are suboptimal, especially for minority and low-income groups.
• Quality is improving; access and disparities are not improving.
• Urgent attention is warranted to ensure continued improvements in quality and progress on reducing disparities with respect to certain services, geographic areas, and populations.
• Progress is uneven with respect to national priorities identified in the HHS National Quality Strategy and the Disparities Action Plan: Quality, Person- and Family-Centered Care, and Promoting Effective Prevention and Treatment of Cardiovascular Disease.
• Making Care Safer, Promoting Healthy Living, and Increasing Data on Racial and Ethnic Minority Populations are lagging.
• Sufficient data is lacking.

- Promoting More Effective Care Coordination and Making Care More Affordable are still not accomplished.
- Disparities related to race, ethnicity, and socioeconomic status present in all priority areas persevere.

Source: U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality Rockville, Maryland, 2011.

Table 7.2 highlights the lack of progress in most areas of health care and data collection for minorities. In addition, this report illustrate that all there was no improvement in health care "disparities" in any of the priority areas targeted.

Insufficient data in 2011 referred to data on certain minority populations, or the lack of "a single national healthcare database [that] collects a comprehensive set of data elements that can produce national and State estimates for all populations subgroups each year" (AHRQ 2011, 1). The data may be old, or not consistently collected every year. One may ask why data problems persist, considering that they were identified in 2003 and every year since then, and why the problem of disparities appears intractable. It should be noted that the above tables do not illustrate disparities in health in general, but instead focus on healthcare. However, there have been no substantial improvements in unequal care either.

Theoretical Contribution

Based on Berger and Luckmann's (1966) theory of the social construction of knowledge, influenced in turn by Gramsci (1971), Mannheim (1936), and Marx (1894), and on theories of hegemony and racial formation (Omi & Winant, 1994), I investigated how the social construction of "health disparities" happened. I interrogated official government documents published between 1979 and 2010, interviewed key informants who were instrumental in influencing and developing the policies to eliminate health disparities, and critically analyzed the discourse in documents and interviews. In addition, I performed a limited content analysis of documents and books to find out whether the “disparities” discourse was dominant. Through my analysis I was able to explain and partly to demystify the construction of “health disparities” that prevailed until recently.

Theoretically and empirically my study contributes a new conceptualization of health disparities to the sociology of health. Empirically, I demonstrated how health inequalities and inequities were transformed into health disparities. I analyzed how this construction happened and became dominant in discourse, policy and programs (from the late 1990’s until recently - 2010) by extending Gramsci’s concept of hegemony and Omi and Winant’s concept of racial formation to an institutional setting, namely the federal government. I conducted an empirical study to illuminate and illustrate how hegemony and racial formation operated in the social construction that transformed health inequalities and inequities into health disparities.

To my knowledge, hegemony, as developed by Gramsci, has not been applied to the health field or the social construction of health disparities by government. I applied and extended Gramsci’s theory to medical sociology, health research and health policy. I showed how the social construction of health disparities happened by conducting in-depth analysis of government documents and by interviewing individuals who participated in developing the concept and subsequent policies and interventions.

In Chapter 2 I mentioned how Gramsci saw the intellectual class controlling the production of ideas that are then adopted by the rest of the population as if these ideas were common sense. My analysis of documents and interviews demonstrated that hegemony still applies and is accomplished today, and has the power to dominate thought and practices of both the intellectual or ruling elite and the rest of the population.

The findings from my study uncovered the importance of the language used in the political discourse. Because of the chosen frame of "health disparities," the persistent phenomenon of health inequalities and inequities continues as intractable today as it was in 1990.

The Role of Discourse in Hegemonic Construction of Knowledge

" In politics, as in religion, whatever is ceremonial or banal strengthens reassuring beliefs regardless of their validity and discourages skeptical inquiry about disturbing issues … language shapes the meaning of what the general public and government officials see" (Edelman, 1977, p. 3).

Edelman's statements illustrate both the importance of language, and acceptance of banal interpretations. After my analysis, I agree with Edelman that government officials and policy-makers use rhetoric and language as the vehicle through which they define and operationalize concepts and disseminate ideas. Additionally they appear to exercise very little 'skeptical' analysis when they apply the concepts they espouse, as illustrated by the widespread use of "health disparities" as a framework devoid of context.

In reference to “health disparities,” we saw that, throughout the documents and the interviews, there were several definitions: some were vague; some were explicitly narrow; some had different meanings for different people or even for the same people in different contexts or countries. All of the definitions omitted root causes of “health disparities.” I posit that the ambiguity of the discourse about “health disparities” was adroitly constructed to accomplish the omission of underlying causes without engaging in (following Edelman’s observation) “skeptical inquiry.”

As I illustrated in Chapter 6 ambiguity allowed those working on disparities (the key informants I interviewed) to reflect their own beliefs into the definition of the term without having to address the causes of the inequalities and inequities. For example, when key informants talked about disparities they imbued the word with their own meanings. Some assumed that the word disparities implied unfairness and injustice – even though they did not use those words in their discourse. Others saw “disparities” limited in scope because the official definitions did not leave room for asking what caused the disparities or who was responsible for them. They did not change or contest the official version. Alternatively, some key informants saw “disparities” as strategic, and used the term for the benefit of those who may have found words such as equity and inequity too inflammatory. For others, “disparities” was the right term for the time, meaning that conservative forces would not have allowed a stronger word. Some informants assumed “disparities” referred to racial and ethnic disparities, while others purposefully stayed away from defining disparities between Blacks and Whites only, to give it a more universal appeal. Some deliberately used the word disparities because it was neutral and it would not elicit opposition, even though they were thinking of equality and equity. In addition to the ambiguity of the term, there appeared to be a process of censorship[34] involved in how individuals talked about “health disparities.”

Different definitions of “health disparities” speak to their social: that they were contingent upon the interests of the individuals and systems involved at a particular time.

Whatever their approach, several of the key informants in my project did not appear to engage in “skeptical inquiry” about the language they used, and thus participated in the hegemonic construction of “health disparities” that we saw in official documents, law, and policy. In Gramsci’s analysis, intellectuals, at different levels, act as functionaries of the state, and as such play an important role in exercising hegemony (Gramsci, 1997). My work agrees with Gramsci’s analysis, and extends it by applying it to the construction of “health disparities” by intellectuals involved in developing official government documents and policies from conceptualization to dissemination. With a few exceptions, the key informants contributed to a definition of “health disparities” that became hegemonic and placed responsibility on individuals with sub-optimal health, not on systems and structures. My study begins to shed light on how intellectuals, who by their knowledge and education might be in a position to connect inequalities to structures such as the political market economy, omitted or skirted this issue when working with or for government or other institutions that protect and maintain the status quo.

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[34] By censorship I mean “the practice of examining and suppressing unacceptable parts” (from Online dictionary).

I did not ask interviewees why they omitted discussion of structural inequalities. However, I did ask why the discourse focused on disparities, not inequalities or inequities. The concept of censorship, although not explicitly mentioned, operated implicitly when some recalled their experiences of what was, in fact, censorship, either self-censorship (internal) or censorship by outside authorities (external). Some informants changed the course of their research when they experienced negative reactions from superiors (Chapter 6, p. 139); others changed the language they used (from inequalities and inequities) to prevent opposition (Chapter 6, p. 138). Consequently, these key informants separated their beliefs from their actions, in effect alienating themselves from their work. The experiences the key informants shared constitute one way in which hegemony, namely through censorship, works on individuals with the power to define the discourse in institutions of government.

The various definitions of “health disparities” forestalled any reference to, or suggestion about, changing underlying structures created by society that facilitate attainment of better health for some and inflict a greater burden of poor health on many others. While all the reports described and documented “health disparities” at length, and proposed disease prevention and health promotion strategies, none mentioned suggestions to address growing social inequalities and inequities and their negative effects on health. Similarly, the key informants, with a few exceptions, did not directly address structural causes, nor did they propose systemic solutions; instead they used the concepts of “disparities” as a strategic way to not upset “the skeptics” (Chapter 6, p. 121). In this process, a problem such as “health disparities” ended up being “deplored but tolerated, rather than attacked in a resolute way” (Edelman, 1977, 7).

Healthy People 2010, and Healthy People 2000 somewhat less so mentioned determinants of health and sometimes through language popular in the international community (Evans, Barer & Marmor, 1994; Wilkinson, 1996; Wilkinson & Marmot, 1999.). HPR 2010 used the words, such as “where people live, work and play”[35] but not the spirit of the social determinants of health. The reports did not explain the meaning of these determinants, and did not make suggestions to address them. The documents did not include, for example, resources to improve daily living conditions, or fair taxation, even though they were discussing, in essence, the negative effects on health from low income and poor education due to unfair distribution of resources. Instead, the reports emphasized personal responsibility and behaviors, followed by interventions directed at individuals, not systems. This pattern of explicit mention of social determinants of health without exploring them was further repeated in documents as well as interviews. It is almost as if, by simply mentioning that there may be underlying causes of “health disparities,” the reports and several of the interviewees considered they had given enough attention to the subject.

Racial formation and class formation. I applied Omi and Winant’s theory of racial formation (Omi & Winant, 1994) to the construction of “health disparities.”

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[35] In Healthy People 2010, for example, a 21/2 page section entitled “Determinants of Health” lists and quickly describes: biology, behaviors, social environment, physical environment, policies and interventions, and access to quality healthcare as having “a profound effect on the health of individuals, communities, and the Nation” (HPR 2010, Vol I, 18-20). On close examination, most of these determinants go back to the individual level, and while the responds describe them in detail, they do not address them systemically anywhere in the text.

Even though Omi & Winant built their racial formation theory in opposition to class (they argued that the class paradigm does not fully explain race, a position I endorse) they saw class as a project linked to social structure (Ibid, p. 68) that, as race, is also a hegemonic project. Therefore I extend their racial formation theory to cover health inequalities and inequities by class, in effect calling for a theory of “class formation” that rearticulates the poor as deficient in their behavior and life choices. This view of the poor has become pervasive and hegemonic, as demonstrated in the health disparities discourse. In the same way, racial formation rearticulates Blacks and ethnic minorities as making poor choices and exercising poor judgment when it comes to their health.

By construing individuals in certain disadvantaged groups as personally responsible for their poor health outcomes, government absolves itself of responsibility to address the social, economic, and political conditions at the core of the “disparities.” In this process, instead of solving the problem of “health disparities” with political initiatives, recommendations focus on altering individual behaviors. The quotation I presented from a government official calling for the need to “build a culture of character” (Healthy People 2000, Chapter 4, p. 55) among the poor and the disadvantaged as prevention is a good example of the discourse used to construct certain individuals as inferior, which constitutes a racial and class formation project that contributes to the social construction of health disparities. At issue here is the focus on changing certain individuals and omitting changing underlying societal conditions.

The racial and class formation processes then become racial and class projects that perform their reification of “inferior” status for individuals in disadvantaged groups. As Omi and Winant say, “a racial project is simultaneously an interpretation, representation, or explanation of racial dynamic, and an effort to reorganize and redistribute resources along particular racial lines” (Omi & Winant, 1994, p.56). In the case of “health disparities,” when responsibility for eliminating “disparities” falls within the purview of the individual and “prevention” interventions – are directed towards changing individual behavior – and these interventions fail, the individuals are blamed, not the interventions. Furthermore, the basic need to redistribute resources that produce and determine better health goes unrecognized and unmet.

I see the “health disparities” paradigm as a class project, as well as a race project where an issue that basically has to do with socioeconomic inequalities and inequities, a social justice issue, was turned into a racial issue. Omi and Winant state:

> The retreat of social policy from any practical commitment to racial justice, and the relentless reproduction and divulgation of this theme at the level of everyday life – where whites are now “fed up” with all the “special treatment” received by non-whites, etc. – constitutes the hegemonic racial project at this time. It therefore exhibits an unabashed structural racism all the more brazen because of the ideological or signification level, it adheres to the principle of “treating everyone alike” (Omi & Winant, 1994, p. 75).

The above statement could very well read, “Where the rich are fed up …with all the special treatment received by the poor”…. And we could say that the hegemonic project of our time involves demonizing the poor and the non-white. My study serves to characterize “health disparities” as a racial and class project sustained by hegemony.

Structural systems of oppression function to oppress not only Blacks but also other groups as well, including poor Whites, because they create the conditions – social structures of inequality and inequity – under which we all make choices that affect our health, conditions that favor a few and are detrimental to many. When it comes to health, structural systems that result in health inequalities and inequities construct health problems as individual behaviors and life-styles and evade systemic, underlying causes. Race and class need to be considered together in analysis and policy. According to Williams (2001) “Race is a poor indicator of differences in economic circumstances” (p. 69), and “data indicates that SES predicts variations fin health for both Blacks and Whites” (Ibid). Studies like Williams’ and others (Williams, Mohammed, Leavell & Collins, 2010) show the intersectional links between race and class. These scholars make the connections between socioeconomic and racial oppression, and understand that to reduce/ eliminate inequities in health our society has to confront economic, racial, ethnic and other inequalities. Progress in our society requires integration of race and class inequalities in analysis and willingness to confront the inequities that these inequalities produce.

Through my research I found a 40 years process where language emphasized certain ideas while omitting others. Consequently, the social construction of “health disparities” occurred as follows:

- By ascribing disparities to ethnic, racial, and other traditionally stigmatized populations, the issue of underlying social inequalities leading to unequal and inequitable health outcomes lost urgency and importance for policy-makers and government agencies.
- By repeated calls for research to find and document disparities, attention diverted from research on underlying causes and interventions to address them. As a result we have ample research focused on recounting disparities, but scant research exploring systemic causes and/or solutions.
- By focusing on health/medical care rather than health, or on diseases rather than on health in the broadest sense of wellbeing instead of focusing on social and economic circumstances that create health inequities, the healthcare system ends up being the only one examined; yet we know that several other systems contribute to health and wellbeing.
- By reducing the social determinants of health to education and income, without addressing political and economic systems that maintain and increase inequalities in these and other areas, the rhetoric expanded while the focus on root causes remained elusive, because addressing inequalities involved controversial issues that were problematic for individuals in policy and government to address (Edelman, 1977).

- By omitting class analysis and the intersection of race and class, the issue of disparities identified mostly with racial and ethnic minority populations did not include poor people who also suffered from poor health and failed to engage a broader constituency.
- By encouraging descriptive research of disparities, very few studies, either conducted or published, attended to structural conditions that served to maintain the unequal system that facilitated accumulation at the top of the hierarchy and deprivation at the bottom, leading to health as well as economic inequities.
- By investing funding and efforts in downstream interventions, such as teaching individuals about diet and exercise, for example, government created the impression that it was doing everything it could, or more than it should, since ultimately it was up to individuals to make a difference in reducing “disparities” that besieged them. Once again, the structural causes were left unexamined.

In the reports I analyzed, interventions focused on provision of information and education to disadvantaged populations, and these approaches became a litany repeated and disseminated decade after decade, as one of the few alternatives on how to influence behavioral and lifestyle changes. The changes expected targeted ethnic and racial minorities, disabled, uneducated, and/or poor individuals. Reports confronted changes at the systems level very rarely, if at all.

Findings from my analysis suggest a concerted effort by people in power to emphasize repeatedly the elements outlined above in official documents that served as the basis for policy, funding, research, and programs at the federal, state, local, and tribal levels. Wide publication and dissemination of official government documents contributed to hegemonic construction of knowledge about “racial and ethnic health disparities” solidified in a reductionist way for a large portion of the public, and neglected the responsibility of government and of policy-makers and researchers. Social justice did not become part of the discourse. Instead, responsibility for change refracted to the individuals who suffered from health inequities. Therefore, systems change was omitted from the discussion and health inequalities and inequities remained unchanged.

Analysis of the interviews also suggested that individuals who made policy, funded research, and produced knowledge, participated in the hegemonic construction of “health disparities,” either actively or passively by failing to contest its limited and limiting definition. Whether because of demands of their positions, loyalty to their leaders, desire to stay involved in the conversation and get ‘something’ accomplished (what some called “pragmatism”), academic constraints, or anticipation of a hostile political climate, very few said that they had made explicit efforts to address root causes of health inequities. And, at least among the key informants, those whose work addressed root causes appeared to have little effect on policy at the national level, at least until recently.

All the individuals I interviewed were highly educated, experienced, knowledgeable and passionate about societal inequalities and inequities. All were cognizant of the importance of social determinants of health. Several expressed their belief that, without changing the present political and economic structures there won’t be health equity, and had expressed these ideas in their research and writing. However, most of the key informants were cautious and unable and/or unwilling to counter the dominant discourse in public, alienating themselves from their own knowledge and academic work. They did not talk about, argue for, or work successfully to achieve the system change needed to eliminate health inequities and inequalities. It appears that policy-makers and institutions working on “health disparities” went along with the government’s definition, and abided by an unwritten rule that inhibited them from mentioning the unmentionable, namely the need for fundamental social change as a prerequisite for an equitable society. The KI’s omissions contributed to the hegemonic notion of health disparities.

Counter currents and counter hegemonic thought and research are always present. Academics, including some I interviewed, are aware of the complexity of the issues involved in the “health disparities” discourse and successfully publish their studies and ideas. However, there is a deep divide between discourse and action. Government policies do not reflect willingness to reduce inequalities and inequities (Williams, 2001). My research adds understanding to how hegemony, through fear as one of its mechanisms, dictates what becomes prevalent in the academic and political discourse.

Differences in Discourse between the United States and the International Community

The United States government accomplished and disseminated the hegemonic and reductionist construction of “health disparities,” that prevailed from the 1990’s until recently, in spite of national and international research and knowledge that exposed unjust social inequalities as root causes of inequalities in health (Marmot & Bell, 2009). Several key informants concurred with the premise that in international discourse equity and inequity have been used and accepted for many years, while disparity appears to be a construction only in the United States. The differences in discourse appear, in this study, when comparing national with international reports published by the World Health Organization; and in the experiences of key informants who have worked in other countries and venues, including the World Health Organization (WHO.

Throughout this study I critiqued one of the major interventions that were initiated with the disparity discourse in the United States, namely the emphasis on diet and exercise to improve health as a main prevention and health promotion strategy. In this area, as in many others, the international discourse differed substantially. While the United States focused on changing individual behaviors as the main initiative to address issues like obesity, the WHO, also concerned with this world-wide problem, took a very different approach to address it. The WHO recommended a comprehensive, multisectoral effort that included sustainable actions at government level to examine policies (food, agriculture, food advertising, etc.) that would make it possible for individuals and communities to enjoy environments that allow them to live healthy lives (World Health Assembly 55.23, 2004).

The WHO initiated much of the international discourse, particularly in Europe, and the Commission on the Social Determinants of Health of the World Health Organization (WHO) reinforced the analysis of the social determinants of health

(Birn, 2009). It is interesting to note that United States policy, in many ways, influenced the WHO, and that many of the individuals who work at the WHO are from the United Sates, and/or work in both venues. Several key informants commented that the language of "health disparities" reflects a widespread ideology that includes individual choice, meritocracy, and an ideal and core value of equality which functions to obscure the causes and realities of widespread systemic inequities. And some added that these values would probably not change.

In summary, my study illustrated how hegemony and racial formation operated in the health sphere from the 1980's until recently. I applied and extended Gramsci's theory of hegemony and Omi & Winant's theory of racial formation and contributed to the fields of sociology, medicine, health services research, and public health through an empirical study. Hegemonic belief in a narrow definition of "health disparities" based on individual choices made mostly by Blacks and other persons of color who were economically and socially disadvantaged and a narrow definition of health as medical care obscured structural inequalities and inequities in health. My study also illustrated how the government used a racial formation process to transform health inequality and inequity into a racial issue, in effect erasing the effects of unequal distribution of economic power and resources. The health disparities project was a racial project through which government interpreted and transformed key elements of social determinants of health into a social construction that was racially based and, for the most part, devoid of social justice.

Implications of This Study for Research and Policy

The social construction of problems besieging our society as the responsibility of individuals is not only present in health; the same mechanisms – blaming the individual victims, not the perpetrating systems and individuals responsible for society's inequities; neglecting underlying structural problems, etc. – explain pervasive and damaging inequities in education, poverty, the justice system, employment, etc. I posit that the reification of the theme of personal responsibility is useful to its creators because it effectively works to mask the underlying structural roots of the problems, which are fundamentally based on inequality and inequity in income and wealth, and oppressive systems like racism, classism, and the like. I would venture to say that, in the United States, hegemony and racial formation play a crucial role in present constructions of all the above problems as well. It is ironic that "personal responsibility" usually is asked of those less able to exercise it, rarely of those with the resources to affect change.

Inequities affect not only individual but also societal resources because of "systematic underinvestment across a wide range of human, physical, health and social infrastructure" (Hofrichter, 2003, p.16) such as poverty, education, housing and employment, among others. Furthermore, by treating social problems as different and separate, as opposed to symptoms of the same underlying systemic inequality, root causes are repeatedly avoided, inequalities become even more extreme as time goes on, and researchers and advocates in different sectors do not work together towards common goals.

Studying root causes as opposed to symptoms requires a different conceptualization of societal problems, and asking different research questions that address upstream issues and include “studying up.” Since the upstream issues are common to many of the problems facing societies today, focusing broadly requires multidisciplinary work across sectors. Health appears to be a good portal to frame problems of broad interest and import and health issues can be used to develop far-reaching and effective transformational policies.

Study Limitations

In retrospect, I see four main limitations in my study: 1) the number of reports I selected for analysis; 2) not including preliminary reports and discussions behind closed doors that were not included in the final, official reports; 3) the brief period of 40 years I included; and 4) the relative homogeneity of the informants I interviewed. I am interested in addressing these areas in future research.

I limited the scope of this study to Healthy People Reports published every ten years, one IOM report, one AHRQ report, one Public Law in the United States and one international report. These documents provided sufficient information to study the period of time in which I was interested. However, analysis of additional reports such as Health United States, published every year, other IOM reports, and all the AHRQ reports, as well as additional WHO reports, would have presented a broader view and maybe an even deeper picture of how social structures remain unexamined in the construction of “health disparities” in the United States. In addition, in order to meet time-lines (and as agreed upon with my committee), I did not make inquiries into the preliminary meetings where the individuals involved debated what concepts to use in the reports, or congressional records of debates about the Public Law I examined. This kind of inquiry would have provided information as to whether there were fundamental disagreements about the language they decided to use in the published reports.

While I chose to study a 40-year period, a longer look would have shown the existence of health inequities and inequalities since any records have been kept. For example, W.E.B. DuBois conducted a study (DuBois, 1956), often cited, where he exposed the great gaps in health and mortality outcomes between Blacks and Whites. Also, in an article for The Nation by W.E.B. DuBois in (1956), he condemned both Democrats and Republicans for their indifferent positions on the influence of corporate wealth, racial inequality, arms proliferation and unaffordable health care. He was, in fact, talking about the structural determinants of health and illness that rarely were mentioned afterwards. Furthermore, these determinants are even more influential today.

Because I only interviewed individuals who were active in policy and academia during the Clinton administration, they held similar ideas. Adding a sample of key informants with opposite political views would help shed light into the opposition that several of the key informants I interviewed feared and catered to, and that contributed to the social construction of “health disparities” that ignored social justice.

Future Research

“Effective political action is likely when it does not disturb power, income, or status hierarchies. More often, politics creates a way of living with social problems by defining them as inevitable or equitable” (Edelman, 1977, 141).

It is not likely that solutions to systemic problems are going to originate in the systems that create them. As I show in my study, the mechanisms that obfuscate and mystify issues are well established and have been for many years; and the individuals within those systems are incapable of changing them, either because they buy into them, or because the political and/or academic environments in which they operate constrict them. For these reasons, it is important to study those systems and the individuals within them, to understand how they construct problems and solutions that, instead of improving social conditions for the populations in need, perpetuate them, or even make them worst. Consequently, they also maintain and improve the status of those most privileged and powerful by displacing responsibility to the most vulnerable, and the dominant discourse continues to state the opposite of what it intends and accomplishes, without effective contestation.

It will be of interest to me to analyze why there was a change in discourse in Healthy People 2020, other than the fact that this report developed at a different time and under different leadership (President Obama). I would also be interested in analyzing whether the difference in discourse translated into addressing root causes of inequalities that affect health for disadvantaged populations.

Before policies change policy-makers need to recognize the need to address root causes of health inequities and inequalities, and this recognition starts with acknowledging that the term “health disparities” as defined contributes to the problem. Since the root causes of “health disparities” implied in the “disparity” concept are usually believed to be concentrated on personal behaviors and lifestyles, as long as this worldview does not change the solutions will continue to aim at changing the way individuals in the lower strata of society behave. Similarly, because of the powerful hegemony attached to the concept of “health disparities,” the individuals and groups negatively affected by inequalities and inequities need to get involved to pressure policy-makers into addressing root causes, not just symptoms of problems.

Progress in reducing inequality and inequity won’t occur until solutions aim to change the way institutions, like government, protect the most privileged in society instead of the most vulnerable. A shift in focus requires a change in discourse that, in turn, reflects a shift in values, and a change in the questions we, as scholars and as a society, ask (Feagin, 2001; Morone, 2005). In future research I plan to continue to interrogate the power of hegemony and how it operates. I plan to disseminate my findings to advocates who can work towards change from below that will benefit those besieged by socio-economic disadvantages.

A shift to an equity frame can potentially direct researchers to ask different questions to investigate root causes at multiple levels of societal problems and to find solutions to address them. For example, researchers can ask how to enact policies that result in equitable institutions and fair societal structures; or, reversely, how policies we implement increase inequity. Researchers can evaluate effects on health when unemployment rises, or when high unemployment and underemployment become the norm; what policies effectively reduce inequalities; the beneficial effects of policies that reduce violence and incarceration, etc. These types of research inquiries can potentially open new avenues of interest geared toward finding alternatives to the present economic and political systems. At the same time, research questions concerning structural problems and solutions can potentially change the discourse in the academy and the polity.

When we consider the power of language (Fairclough, 1989) in the social construction of problems and solutions, it seems plausible that a change in discourse will move the tide towards solutions that require social change for the benefit of all in society. As exemplified in Healthy People 2020 and in some of the most recent research language of equity and inequity, change in discourse is happening. There is hope that when the focus of problems and interventions shifts to societal responsibility, solutions might be located at the systemic level. We will then transcend inequities in health and in other areas. We will be dealing comprehensively with the underlying structures that cause and sustain many of the societal problems we face today. However, as we saw at the beginning of this chapter, important policy and opinion makers (like President Clinton and former Surgeon General David Satcher) may be using slightly different language and slightly different initiatives while still sidestepping structural inequalities.

Strands of thought are already moving in the direction of expanding boundaries between academic disciplines to conduct inter- and multi-disciplinary research. Most importantly, multi-sectoral approaches appear most appropriate and would lead away from addressing symptoms and toward addressing common causes. Some may argue that the seeds of change are already present, and that the time is ripe for their pursuit. It is time for sociologists and other scholars to take this opportunity to ask different and relevant questions and work with other sectors to address the unjust consequences of growing social inequality, the root of myriad social problems that besiege us now, as they have for centuries.

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Appendix I. Preliminary Interview

Introduction: During the later years of the Clinton administration and the beginning years of the Bush administration there was an added emphasis on the concept of health disparities. This seemed to be a conceptual as well as linguistic shift from inequalities and inequities in the discourse about health. In my research I aim to find out how this apparent shift happened.

In your role as a Washington insider and/or academic involved in developing and writing reports and policy I am interested in your recollection of events at the time.

1. What was your role during the Clinton administration in relation to the development and implementation of the “Minority Health and Health Disparities Research and Education Act of 2000” (Public Law 106-525, 106th congress, 2nd session)?

2. What were the antecedents to this law? Namely, what /who instigated the discussion that put health disparities on the agenda?

3. Who were the people and/or organizations that proposed and supported the health disparities concept? Who was behind the health inequities concept? What were their arguments? For example, individuals in Congress, researchers, interest groups, think tanks, NGOs, etc.?

4. What research influenced and was used to justify the disparity language? And, could different research have influenced a different policy -- as in using health inequity instead of health disparity?

5. What agreements/disagreements happened during the discussions about the use of the word disparity?

6. How did different interest groups/constituencies receive the law?

7. What definition did you favor/ and what were your reasons?

8. In your opinion, how has implementation of the law influenced health outcomes?

9. Do you have any other comments or are there any other questions you wish I had asked?

10. Can you recommend other individuals for me to interview? And/or documents I may want to analyze?

Thank you very much for your participation in this study.

Appendix II. Sample Letter to Key Informants

Sonia P. Bettez
PhD Candidate
PO Box 90
Corrales, NM 87048-0090
Date:

(Name and title, if available)
Position
Address:

RE: Project title: The Social Transformation of American Health Inequities: Understanding the Dominant Disparities Discourse in the United States

Dear

Thank you very much for considering participating in my study. This is a doctoral dissertation project. I am conducting between 15 to 20 interviews in the US with policy-makers and researchers in government and academia who were involved in the linguistic and conceptual use of the term disparities instead of inequities and/or inequalities in health during the Clinton administration.

The purpose of these interviews is to document a range of perspectives about how health policy is made at the federal government level and the role of academic researchers in the development of policy. This information will contribute to understanding how the construction of health disparities happened. The study will provide a theoretical contribution to the literature in the sociology of health. The results will be published as part of my PhD dissertation, and the work will also be used to make recommendations about health policy making.

I will send the interview questions ahead of time. These will be the basis of our conversation. I will contact you by e-mail or/and by telephone to arrange a time for the interview. It will take from 30 minutes to an hour.

Your participation is voluntary. I will send the interview questions ahead of time I will send an informed consent form for your signature both electronically and by regular mail.

If you have any questions, please e-mail me at spbettez@unm.edu or call me at (505) 890-7121.

Sincerely yours,

Sonia P. Bettez, PhD Candidate

RWJF Fellow and Mellon Fellow

University of New Mexico

Attachment: Informed consent form for your signature

Appendix III. Titles of Scientific Papers the IOM Commissioned in 2002 and Used as Part of the Research for the "Unequal Treatment Report"

1) Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and a Consideration of Causes. H. Jack Geiger, M.D., City University of New York Medical School.

2) Racial and Ethnic Disparities in Healthcare: A Background and History. W. Michael Byrd, M.D., M.P.H., Linda A. Clayton, M.D., M.P.H. Division of Public Health Practice Harvard School of Public Health.

3) The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives. Jennie R. Joe, Ph.D., M.P.H. Native American Research and Training Center University of Arizona.

4) Patient-Provider Communication: The Effect of Race and Ethnicity on Process and Outcomes of Healthcare. Lisa A. Cooper, M.D., M.P.H. and Debra L. Roter, Dr.P.H. Johns Hopkins University, Baltimore, Maryland.

5) The Culture of Medicine and Racial, Ethnic, and Class Disparities in Healthcare Mary-Jo DelVecchio Good, Ph.D., Professor of Social Medicine. Cara James, B.A. Byron J. Good, Ph.D., Professor of Medical Anthropology. Anne E. Becker, M.D, Ph.D., Assistant Professor of Medical Anthropology. Department of Social Medicine, Harvard Medical School.

6) The Civil Rights Dimension of Racial and Ethnic Disparities in Health Status. Thomas E. Perez, J.D., M.P.P.1 Clinic Director and Assistant Professor of Law University of Maryland School of Law.

7) Racial and Ethnic Disparities in Healthcare: Issues in the Design, Structure, and Administration of Federal Healthcare Financing Programs Supported Through Direct Public Funding. *Sara Rosenbaum.*

8) The Impact of Cost Containment Efforts on Racial and Ethnic Disparities in Healthcare: A Conceptualization. Thomas Rice, Ph.D. Department of Health Services UCLA School of Public Health.

9) Racial and Ethnic Disparities in Healthcare: An Ethical Analysis of When and How They Matter. Madison Powers and Ruth Faden. The Kennedy Institute of Ethics Georgetown University.

The above papers are available online and as a CD companion to the printed copy of the report

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