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## **Foreword: envisioning health disparities.**

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### I. INTRODUCTION

No one approves of it. Our laws prohibit it. Yet racism will not go away. We continue to demonstrate that a colorblind society is just a society where color lurks in the blind spot. Disparities in healthcare offer a telling illustration of how durably racism is woven in our social fabric, and how easy it is for subtle, unconscious differences in treatment to add up to significant disparities in outcome. Disparities also give us an opportunity to see health differently. Instead of focusing on the outcomes of individual cases, disparities invite us to examine the social structures and processes through which the level and distribution of health are determined. Like racism, health is to a considerable degree a social product, reflecting how we order the world rather than our biological or genetic limits.

The articles in this Symposium reflect a growing willingness in health and healthcare research to place individual outcomes in a larger, ecological framework. (1) They are part of a process of social learning, a process of changing the focus from the final pathological outcomes that now more or less dramatically define our problems to the durable and flexible eco-social machinery that generates the problems and determines how they will be distributed. Solving problems, we are learning, is on its own insufficient: the problem-generating machinery simply makes new ones. The trick is to study the problem production system, and find structural interventions that begin to disrupt it. (2) No single law review article can be expected to provide the solution to the problem of health disparities, but each article in this issue is a contribution to our ability to understand the problem and make that understanding salient to policy-makers and the public. In this Foreword, I suggest that the most important job of the health law or health services scholar tackling health disparities is to consider how law operates in relation to other social determinants as a cause of disparities, (3) and how it may be used as a structural intervention to influence the social processes that produce them. (4)

### II. RACISM AS A STIGMA

Race as described in the articles in this Symposium is essentially a form of stigma, "an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual." (5) Both prejudice--negative attitudes--and discrimination--overt negative behavior--may flow from and help enforce a stigma, but the real power of stigma as a form of social control is that the negative valuation of the stigmatized trait is built into people's basic understanding of the world: it is not an opinion, but a fact; it is not asserted, but taken for granted. Racism can thus be seen as a social process that continues to operate throughout social life even when specific manifestations are universally disfavored. Jim Crow has been repudiated, and racial equality is a valued norm, yet a country full of people who believe in equality and oppose segregation remains physically divided along racial lines.

The question of whether race has sufficient biological reality to require or justify its active consideration in clinical research is still being debated, (6) but we cannot advance public health or healthcare without accepting the reality of racism in our society. (7) As Ross and Walsh point out in their contribution to this Symposium, racism as a cultural force could be producing disparities even if race as a biologic factor makes no contribution. (8) The American concept of race is really quite a formidable achievement. Given how undramatically we

Americans ultimately differ in shape, genes, culture, values and so on, a visitor from another planet might well be impressed with how intricately we can sort each other by subtle differences in shading and social position. A great deal of effort has gone and continues to go into making sure that we can recognize, respect and enforce racial differences. As happens with stigmas, we are tacitly taught by example and experience to recognize the traits that define race, and that divide us into different social groups; we learn that certain "races" are spoiled--in a variety of ways that are discreditable, dysfunctional, distasteful--and we quite naturally take on the role of enforcement: those in the dominant racial group by exclusionary practices, those in the stigmatized groups by withdrawal and the many other self-lacerating forms of stigma adjustment. (9)

Racism as stigma can be difficult to police under our law of race relations. Our law prohibits "discrimination," which it defines principally with reference to intentional, overt acts. (10) The power of stigma as a form of social control is that it is decentralized--everyone enforces it--and hidden--it resides in our assumptions about what is real in the world. (11) There is rarely a need for anything so gross as overt, intentional discrimination: stigma can be quite well enforced by those with relative power through the day to day exercise of discretion over matters such as whom to mentor, or stop and frisk--or refer for specialist care. As Balsa and colleagues describe here, physicians as a group can assign African Americans to inferior care without more than a few being conscious of any racial bias. (12) Researchers can continue to exclude or include racial minorities in their investigations in problematic ways, even as they accept ethical precepts that are meant to inculcate racial sensitivity and fair treatment. (13) Because it is decentralized and pervasive, racism as stigma "happens" without the conscious or intentional action of the enforcer. It leaves no smoking gun behind: racism as stigma is all effect and no cause.

But law, one fears, does more than just fail to prevent the operation of racism. It may well also be a potent contributor to the force and invisibility of racism in the workings of American culture and institutions. It is law, after all, that has embodied the view that racism equals intentional discrimination, and that therefore excludes from consideration the racist social processes that lead to disparities. It is law that validates color-blindness as a value and goal. It is law and law enforcement practices that have traditionally favored physician autonomy over fair healthcare access. (14) As critical race theorists have exhaustively demonstrated, race and White racial advantage can be found throughout the law. (15)

The notion of stigma also illuminates the behavior of the stigmatized, and its importance in reducing racism and its effects. Several of the authors here note the role of care-avoidance and an unwillingness to make demands in poorer healthcare utilization and quality among Blacks and Latinos. This is what is called in the stigma literature "self-discrimination," the most insidious of all stigma's enforcement mechanisms. (16) Racism may also create "noise" in the relationship between provider and patient, making it harder for individuals to seek out or rely on the advice of their doctors. (17) Law can play a role in helping individuals resist and reject stigma, but only if they are prepared to rely on it. If the legal system is seen as part of the problem, (18) or legal remedies are inadequate (as Rosenbaum and Teitelbaum argue), (19) law will not empower the targets of stigma to resist.

### III. HEALTH DISPARITIES & SOCIAL EPIDEMIOLOGY

Health disparities have the potential to reveal another socially elusive truth, the pervasive operation of fundamental social determinants of health. (20) As Bobinski explains here, (21) our cultural tendency is to understand health in individualistic terms, with a significant focus on healthcare and individual choice as the prime drivers of good outcomes. What an individualistic and healthcare-centered view overlooks (and indeed obscures) is the extent to which the overall pattern of individual health fates is determined by structural factors in the social and physical environment. (22) Healthcare disparities are important, but they are merely one result of (and only one of many factors contributing to) disparities in the level and distribution of health in the population.

Social epidemiology is bringing ever more theory and data to bear on the difference between the causes of cases--why a particular person gets a particular disease--and the causes of incidence --why a society or sub-population

exhibits a given level and distribution of health. (23) The outlines of the story are becoming reasonably clear: health outcomes reflect a complex interaction of individuals with their social and physical environment over time. Social position, and the characteristics of the society in which that position resides, have a steady influence on exposure to health stressors and the possession of resources helpful to withstanding stress. Many if not most of the "goods" that help us maintain good health are collective ones that none of us on our own can obtain: supportive social networks, collective problem-solving ability, clean air, freedom from crime and so on. Yet despite the demonstrable and well-accepted importance to health of providing the conditions in which we can be healthy, (24) most of our money and attention in the health realm still goes to purchasing individual health services keyed to our individual risk profiles.

Just as in the instance of racism, law may be examined for its role in creating and maintaining the social structures that determine population health. (25) Law may also be investigated for its role in mediating the transformation of social position into health outcomes. (26) Law will rarely be the primary force creating, sustaining or operationalizing the social determinants of health, but it will rarely be entirely absent and may often be a good place to begin making change.

#### IV. INTERVENING

Supporting real change is the proper goal of disparities research. An ecological understanding of health implies an ecological approach to health promotion. The particular diseases or racial imbalances that emerge at the end of the processes of health or racism are the symptoms, not the disease, and unless we get at root causes and problem-generating processes, we are unlikely to make much headway: the particular problems we solve will just be replaced by new and different ones. To reduce disparities, it is necessary to understand the processes that produce them and identify key pressure points where the processes can be interrupted.

The articles by Balsa and colleagues, (27) and Trubek and Das, (28) argue that quality is such a pressure point. Balsa and colleagues see disparities arising primarily from the interaction of biased or faulty heuristics and clinical uncertainty, a subtle and perspicacious point. Theirs is a proposal for structural change: Rather than individual bias, they focus on changing the decision processes that allow racism room to operate. By developing better practice guidelines for all patients, the medical profession can reduce the occasions on which professional discretion will be used to sort people by race.

Trubek and Das likewise point to the value of an emerging "quality/equity" norm, but noting the limits of past litigation and local organizing efforts to stamp out disparities, emphasize the need to embed the new norm in new forms of healthcare governance. It is a central insight of ecological theories that behaviors and outcomes are not separable from the institutional and normative systems in which they occur. All forms of governance embody and transmit assumptions about human motivations, values and the best means of managing the sorts of matters the institution is established to oversee. (29) Trubek and Das see many signs of hope that a new and better system can emerge from the pursuit of quality, one that will give greater authority to patients and to non-hierarchical teams of healthcare professionals in clinical matters, "physician-executives" and advocates in managed care, and private quality-improvement organizations in healthcare regulation and finance. Reforming American healthcare delivery is the sort of task that would make Pollyanna a pessimist, but hope--and the sort of practical models Trubek and Das describe--are essential tools for change.

One of the challenges posed by healthcare disparities is the difficulties we have in organizing healthcare for everyone. The notion of disparity in this Symposium goes beyond race, and two of the articles about the disparity between mental health and other care offer instances of the difficulties and unintended consequences that beset regulation. Davoli argues that the exclusion of in-patient care from Medicaid helped fuel inappropriate deinstitutionalization and poor care for people with mental health problems, creating discrimination in access to care based on diagnosis. (30) Jacobi shows here how the benefits of mental health insurance parity legislation are

being threatened by the emergence of managed behavioral health systems. While managed care has largely undermined the argument that parity is too costly, the proper measure of parity's success must be real access to quality care. (31) As in the healthcare system overall, cost efficiency and quality of care can be complementary, but achieving both ends is not easy.

There is a risk that the disparities debate will focus too much on healthcare and not enough on health. Since healthcare is not the principal determinant of population health, eliminating healthcare disparities will not by itself eliminate health gaps. Examining the health and access problems of the Latino elderly, Wallace and Villa complement detailed suggestions for healthcare policy reform with a call for new public health efforts to address the structural determinants of poor health in the population. Older people will not exercise if they are afraid to be outdoors. They cannot eat a healthy diet if there are no supermarkets in the neighborhood offering affordable fresh fruits and vegetables. (32)

Teitelbaum and Rosenbaum are, at least on the surface, resolutely non-structural in the intervention they suggest. They argue for amending the 1964 Civil Rights Act to use the same definition of public accommodation as is now found in the Americans with Disabilities Act. (33) There are serious limits to what anti-discrimination law can do, especially in a world in which enforcement is limited by resource and legal strictures, (34) but it would be wrong to dismiss this suggestion as a call to repeat past mistakes. Even when we try to focus on social determinants and processes, law should still prohibit discrimination and individuals who are hurt by discrimination need a current, effective remedy. Moreover, law and the law reform process can be places where advocates argue for deeper change, which is a key point made by Rosenbaum and Teitelbaum. And of course, even keeping in mind the possible limits of litigation as a tool of social mobilization, (35) arguing for a remedy for physician discrimination can be an opportunity for public debate about the definition of discrimination and its prevalence. Certainly, law has been an important tool outside the United States in the vigorous health and human rights movement. (36) If racism can indeed be seen as a stigma, one of the most direct structural interventions being discussed today is reparations for slavery. (37) The idea of reparations is about far more than a pay-back for a distinct historical wrong. While it begins with a recognition that slavery is a wrong that still wants a remedy, and that its effects continue to be felt today, reparations is essentially a forward-looking intervention, and an optimistic one. White Americans need to go through a process of what restorative justice scholars call "reintegrative shaming." (38) The full horror of slavery, and its lingering effects, must be acknowledged; our (by which I mean White people's) continued advantage and active reproduction of racial stigma must be seen. The purpose, however, is not the assignment of blame and the enforcement of guilt, but creating the possibility of freeing ourselves from the stigma of racism by learning to see it in daily operation. (39)

## V. MAKING THE SOCIAL VISIBLE

Both racism and individualism in matters of health derive much of their power from their uncontestedness. (37) Invisible social forces are much more powerful than those we see. Both social science and epidemiology have the capacity to bring the hidden figure in the carpet into the foreground of our consciousness to help change the social understanding of racism and the determinants of health. It is natural to think of any sort of structural critique as "big" (or "too big"), as in "what you're really saying is that to improve healthcare access we have to eliminate racism and poverty?" The fallacy in that response is in the premise that racism and poverty are in fact "big" factors in the sense of being powerful forces external to our day to day existence and difficulties. What scholarship can do, and in this Symposium does, is to show that "big" factors like racism or the stigma of mental illness are in fact operationalized every day in the countless small decisions and actions that form our society. We don't have to look to the very roots of our society to find and address these stigmas: they are right here in our thoughts and actions. If we can see that, we can begin to think and act differently, and we can use the law creatively and effectively to foster more such recognition and change.

(1) See, e.g., SOCIAL EPIDEMIOLOGY (L. Berkman & I. Kawachi eds., 2000); WHY ARE SOME PEOPLE

HEALTHY AND OTHERS NOT? (Evans et al. eds., 1994).

(2) See generally Scott Burris, Introduction: Merging Law, Human Rights, and Social Epidemiology, 30 J.L. MED. & ETHICS 498 (2002).

(3) Law may contribute to racial and other health disparities in at least two important ways: law may be a mechanism through which deep social structures are operationalized in health disparities, and law may be contributing to the existence of those deep social determinants. See Scott Burris et al., Integrating Law and Social Epidemiology, 30 J.L. MED. & ETHICS 510 (2002).

(4) "Structural interventions ... refer to interventions that work by altering the context within which health is produced or reproduced." Kim M. Blankenship et al., Structural Interventions in Public Health, 14 Supp. 1 AIDS S11 (2000); see also Esther Sumartojo, Structural Factors in HIV Prevention: Concepts, Examples, and Implications for Research, 14 Supp. 1 AIDS S3 (2000).

(5) Gregory M. Herek, Thinking About AIDS and Stigma: A Psychologist's Perspective, 30 J.L. MED. & ETHICS 594 (2002). For a review of other definitions current in the literature, see Bruce Link & Jo Phelan, Conceptualizing Stigma, 27 ANN. REV. SOCIOLOGY 363, 364-65 (2001).

(6) See Barbara A. Noah, The Participation of Underrepresented Minorities in Clinical Research, 29 AM. J.L. & MED. 221 (2003).

(7) For a discussion of the distinction between race and racism, see Nancy Krieger, Does Racism Harm Health? Did Child Abuse Exist before 1962? On Explicit Questions, Critical Science, and Current Controversies: An Ecosocial Perspective, 93 AM. J. PUB HEALTH 194 (2003).

(8) See Lainie Friedman Ross & Catherine Walsh, Minority Children in Pediatric Research, 29 AM. J.L. & MED. 319 (2003).

(9) ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY (1963); Link & Phelan, *supra* note 5.

(10) See, e.g., Linda Hamilton Krieger, The Content of Our Categories: A Cognitive Bias Approach to Discrimination and Equal Employment Opportunity, 47 STAN. L. REV. 1161 (1995). It is quite possible to do things differently. In Canada, to take one close example, the Employment Equity Act requires employers to engage in a self-audit process to identify systemic barriers to equality in the workplace. See Canadian Human Rights Comm'n, Framework for Compliance Audits Under the Employment Equity Act: Audit Process and Assessment Factors, available at <http://www.chrccdp.ca/ee/audit-framework.asp> (1996).

(11) Scott Burris, Disease Stigma in U.S. Public Health Law, 30 J.L. MED. & ETHICS 179 (2002).

(12) Ana I. Balsa et al., Clinical Uncertainty and Healthcare Disparities, 29 AM. J.L. & MED. 203 (2003).

(13) See Noah, *supra* note 6; Ross & Walsh, *supra* note 8.

(14) Joel Teitelbaum & Sara Rosenbaum, Medical Care as a Public Accommodation: Moving the Discussion to Race, 29 AM. J.L. & MED. 381, 382-83 (2003).

(15) KIMBERLE CRENSHAW, CRITICAL RACE THEORY: THE KEY WRITINGS THAT FORMED THE

MOVEMENT (1995).

(16) See, e.g., GRAHAM SCAMBLER, *EPILEPSY* (1989).

(17) See Balsa et al., *supra* note 12, at 204.

(18) See, e.g., Steven P. Wallace & Valentine Villa, *Equitable Health Systems: Cultural and Structural Issues for Latino Elders*, 29 *AM. J.L. & MED.* 247, 256 (2003).

(19) See Teitelbaum & Rosenbaum, *supra* note 14.

(20) B.G. Link & Jo Phelan, *Social Conditions as Fundamental Causes of Disease*, *J. HEALTH & SOCIAL BEHAVIOR* 80 (Extra Issue 1995).

(21) Mary Anne Bobinski, *Health Disparities and the Law: Wrongs in Search of a Right*, 29 *AM. J.L. & MED.* 363 (2003).

(22) Geoffrey Rose, *Sick Individuals and Sick Populations*, 14 *INT'L J. EPIDEMIOLOGY* 32 (1985).

(23) *Id.*; see, e.g., M. Susser & E. Susser, *Choosing a Future for Epidemiology: I. Eras and Paradigms*, 86 *AM. J. PUB. HEALTH* 668 (1996); M. Susser & E. Susser, *Choosing a Future for Epidemiology: II, From Black Box to Chinese Boxes and Eco-Epidemiology*, 86 *AM. J. PUB. HEALTH* 674 (1996); I. Kawachi, *Income Inequality and Health*, in *SOCIAL EPIDEMIOLOGY* 76 (I. Kawachi & L. Berkman eds., 2000).

(24) See *INST. OF MED., THE FUTURE OF PUBLIC HEALTH* (1988).

(25) See Burris et al., *supra* note 3, at 515-18.

(26) See, e.g., Steven P. Wallace et al., *The Consequences of Color-Blind Health Policy for Older Racial and Ethnic Minorities*, 9 *Stanford L. & Pol'y Rev.* 329 (1998).

(27) Balsa et al., *supra* note 12.

(28) Louise G. Trubek & Maya Das, *Achieving Equality: Healthcare Governance in Transition*, 29 *AM. J.L. & MED.* 395 (2003).

(29) See, e.g., Sevgi Aral et al., *Health and the Governance of Security: A Tale of Two Systems*, 30 *J.L. MED. & ETHICS* 632 (2002). See generally LES JOHNSTON & CLIFFORD SHEARING, *GOVERNING SECURITY: EXPLORATIONS IN POLICING AND JUSTICE* (2003) (elaborating on the concept of governance and its influence on behavior).

(30) See Joanmarie Ilaria Davoli, *No Room at the Inn: How the Federal Medicaid Program Created Inequalities in Psychiatric Hospital Access for the Indigent Mentally Ill*, 29 *AM. J.L. & MED.* 159 (2003).

(31) John V. Jacobi, *Parity and Difference: The Value of Parity Legislation for the Seriously Mentally Ill*, 29 *AM. J.L. & MED.* 185 (2003).

(32) Wallace & Villa, *supra* note 18.

(33) Teitelbaum & Rosenbaum, *supra* note 14.

(34) See, e.g., Kathryn Moss et al., *Unfunded Mandate: An Empirical Study of the Implementation of the Americans with Disabilities Act by the Equal Employment Opportunity Commission*, 50 U. KAN. L. REV. 1 (2001) (examining enforcement of Title I of the ADA). Trubek and Das discuss the history of civil rights enforcement in healthcare access. Trubek & Das, *supra* note 28, at 397-99.

(35) Compare GERALD N. ROSENBERG, *THE HOLLOW HOPE: CAN COURTS BRING ABOUT SOCIAL CHANGE?* (1991) with MICHAEL W. MCCANN, *RIGHTS AT WORK: PAY EQUITY REFORM AND THE POLITICS OF LEGAL MOBILIZATION* (1994).

(36) See, e.g., Alicia Ely Yamin, *Protecting and Promoting the Right to Health in Latin America: Selected Experiences from the Field*, 5 HEALTH & HUM. RTS. 117 (2000). See generally LAWRENCE GOSTIN & ZITA LAZZARINI, *HUMAN RIGHTS AND PUBLIC HEALTH IN THE AIDS PANDEMIC* (1997) (explaining that defending human rights is critical in the fight against the AIDS pandemic).

(37) See, e.g., Alfred Brophy, *The World of Reparations: Slavery, Reparations in Historical Perspective*, 3 J. L. IN SOCIETY 105 (2002).

(38) See generally *RESTORATIVE JUSTICE AND CIVIL SOCIETY* (H. Strang & J. Braithwaite eds., 2001).

(39) The metaphor of disparity is also used in this issue by Janna C. Merrick, *Spiritual Healing, Sick Kids and the Law: Inequities in the American Healthcare System*, 29 AM. J.L. & MED. 269 (2003), who argues that spiritual exemptions from vaccine and treatment laws should be seen as discriminating against children denied standard care because of the beliefs of their parents, and by Robin Fretwell Wilson, *Uncovering the Rationale for Requiring Infertility in Surrogacy Arrangements*, 29 AM. J.L. & MED. 337 (2003), who considers whether laws limiting surrogacy to infertile couples discriminate rationally or unfairly.

(37) See, e.g., Scott Burris, *The Invisibility of Public Health: Population-Level Measures in a Politics of Market Individualism*, 87 AM. J. PUB. HEALTH 1607 (1997).

Scott Burris, James E. Beasley Professor of Law, Temple University Beasley School of Law; Associate Director, Center for Law and the Public's Health at Georgetown and Johns Hopkins University; Visiting Fellow, Regulatory Institutions Network, Research School of the Social Sciences, Australian National University. The author thanks Helen Watchirs for helpful comments on this Foreword.

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