

Health Disparities & the Body Politic



A series of International Symposia

Spreading the Health:
Government's Role in Addressing Health Disparities

Investigating Health Disparities:
New Agendas for National Health Research Institutes

Making Disparities Count:
From Government Statistics Systems to Action



*Organized by the Working Group on Health Disparities at the
Harvard School of Public Health*

Health Disparities & the Body Politic

A Series of International Symposia



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Health Disparities & the Body Politic is based on a series of three international symposia which took place on March 3, April 14 and May 5, 2005. More information about the symposia, videoarchives of the three sessions, and this book may be found for free on the internet at www.hsph.harvard.edu/disparities

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Foreword

Barry R. Bloom, Ph.D.
Dean, Harvard School of Public Health



Barry R. Bloom, Ph.D.

In the seventeenth century, the English political philosopher Thomas Hobbes portrayed life in a “state of nature” as “solitary, poor, nasty, brutish, and short.” In Hobbes’ time, only half a billion people inhabited the planet. Life expectancy in England averaged 32 years.

In the twenty-first century, much of Hobbes’ pungent description sounds obsolete. Our crowded and globalized planet of 6.4 billion inhabitants is no longer a “solitary” place. And in most nations, life is no longer “short.” In 1900, for example, life expectancy in the U.S. was 47 years; it is now 77.6 years. Indeed, life expectancy at birth has increased more in the past century than in all previous centuries.

Yet the world Hobbes described is not entirely gone. Today, fully 83% of the Earth’s population lives in a diverse mix of what are termed “developing countries and transition economies.” Nearly one in five worldwide – an estimated 1.1 billion people – live in extreme poverty, subsisting on less than \$1 a day. And though infant mortality has diminished in all countries of the world (with the major exception of sub-Saharan Africa), other health

problems in developing and industrialized countries have converged, including the increasing burden of non-communicable diseases and the inexorable rise in health costs.

Perhaps most discouraging: despite enormous gains in quality of life stemming from advances in public health and medicine, disparities in health – in health status, life expectancy, access to knowledge and medical technologies, and access to care – have widened everywhere, both within and between countries. There are more than a billion people in 2005 whose life can be described in wretched Hobbesian terms. That demands a rethinking of our health priorities.

Traditional economic theory holds that if a country gets its macroeconomics right, it will improve the health of its people. Growing evidence, however, suggests this conventional wisdom is wrong. Not only does the health status of people have an enormous impact on a nation's economic and social development, but without specific policies aimed at reducing health disparities, indicators for overall economic prosperity and average health may improve even as a nation's health disparities persist or become more extreme. Can it be morally acceptable, let alone politically stable, to have a world in which there is a 20-fold difference in infant mortality and a 21-year gap in life expectancy between the 51 high-income countries and the 66 poorest countries? What has become of the spirit of American democracy when differences in average U.S. life expectancy between counties across states varies by 10-15 years?

The Harvard School of Public Health is dedicated to its mission – to advance the public's health through learning, discovery, and communication – both within the United States and around the world. Our community of outstanding scholars represents fields as diverse as basic biologic science, quantitative population-based science, and social and economic research. Addressing and redressing disparities in health is an institutional thread that weaves together everything we do. That common purpose connects and motivates us all.

For any academic institution, a key challenge is to translate knowledge into action, institutional awareness into public concern, data into policy. One important advantage of universities – and, we would like to believe, Harvard in particular – is their unique capacity to reach out and engage scholars and leaders from all over the world: to share knowledge and experience, to learn

from each other's perspectives, to think together how we can make progress on today's most critical issues. Under the leadership of three faculty members – Nancy Krieger, Professor in the Department of Society, Human Development and Health (SHDH); Lisa Berkman, Professor and Chair of SHDH; and David Studdert, Associate Professor of Health Policy and Management – the Harvard School of Public Health organized a series of symposia each addressing a different aspect of disparities in health, an issue that we believe to be one of the most urgent of our time. We focused on concrete actions that governments can take to reduce disparities in health in the realms of policy making, support for critical research, and collection of relevant data.

The symposia were intended to sound a call to action. Our hope is that by strengthening ties between academics and a broader set of actors, we might together make real change in the lives of everyone in this world, but particularly the poor and disadvantaged. The symposia, and this booklet, reflect the obligation of all of us to the commitment stated in the Preamble to the Constitution of the World Health Organization and engraved in four languages on the marble walls of the Harvard School of Public Health's François-Xavier Bagnoud Building:

“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions.”

Introduction

Nancy Krieger, Ph.D.
Professor of Society, Human Development and Health
Harvard School of Public Health

Social inequality kills. It deprives individuals and communities of a healthy start in life, increases their burden of disability and disease, and brings early death. Poverty, discrimination, inadequate medical care, and violation or neglect of human rights: all act as powerful social determinants of who lives and who dies, at what age, and with what degree of suffering. The obvious follow-up question is: Who should be doing what to fix this problem?



Nancy Krieger, Ph.D., Symposia Chair

One possible – and controversial – answer to the *who* part of the question is: government. To examine this idea, and the corollary of what governments could and should be doing, a subcommittee of the Harvard School of Public Health Working Group on Health Disparities organized a series of three international symposia on “Health Disparities & the Body Politic.” Our subcommittee, which I chaired, focused the series on three specific issues: policies, research, and data. This report, ably prepared by science and public health journalist Madeline Drexler, author of *Secret Agents: The Menace of Emerging Infections* (Penguin, 2003), encapsulates key issues raised in the symposia. In this introduction, I briefly provide some historical background to give context to contemporary debates.

As a starting point, it may seem obvious that governments should be taking action in these areas. But we are confronted by the sorry fact that, despite centuries of evidence that poverty and social injustice harm health, only in the past decade has concern with social inequalities in health entered the mainstream public health agenda.¹⁻³ To advance work on redressing health inequities in the U.S. and globally, we organized these symposia to learn more about these new initiatives, how they came about, and what can be done to strengthen them. We invited participants from the Americas, Europe, Africa, and Asia, with the intent of sparking dialogue that will expand our sense of possibilities along with our commitment to tackling social inequities in health.

Clearly, we are not the first to raise questions about government's influence on – and responsibility for – population health.^{4,5} For millennia, keen observers across a wide range of societies and viewpoints have noted connections between the state of the body politic and people's bodily and mental health. For example, the famed Hippocratic text, *Airs, Waters, Places*, likely written in the 4th century BCE, roundly asserted that Greek democracies had the healthiest populations because democracy spurred individual initiative and an interest in taking care of oneself, whereas despotic rule fostered fatalism and bodily neglect. This claim of Greek superiority nevertheless applied only to the well-being of the relatively small minority of free male citizens and not to that of their female counterparts or to the far more numerous and less healthy metics and slaves.⁶⁻⁸ Another foundational text, *The Yellow Emperor's Classic of Internal Medicine*,⁸⁻¹⁰ compiled in China between the 2nd century BCE and 7th century CE, by contrast stated that proper observance of hierarchy, especially by peasants toward their rulers, was essential for good health – and tellingly framed disease as akin to rebellion.^{9,10}

Not until the 17th century CE, however, did the metaphorical link between the health of our bodies and the body politic become literal. The first text to use data to make this connection, the *Political Anatomy of Ireland*,¹¹ was written in the 1670s by the English physician, anatomist, and economist Sir William Petty (1623-1687).^{11,12} In this provocative treatise, Petty took two unprecedented steps: 1) he provided numerical evidence linking societal resources to health status, and 2) he argued that the body politic could be scientifically studied – just like any other body of the biological sort.¹¹⁻¹⁵ This work helped set the basis for systematic investigation of connections between the state and population health. Indeed, the word “statistics” is derived from the word “state”; coined in 1749 by the German statistician and political

scientist Gottfried Achenwall (1719-1772), the term referred to information (including health data) that was vital to rulers in procuring and dispensing state resources and was of such great value as to be deemed a state secret.⁴ (p. 151).¹⁶

With the rise of the modern public health movement in the early 19th century, these statistics were finally brought out into the open and became a focus of public concern and agitation – especially given the all-too-evident wretched physiques of the newly emerging working class, who were crowded into rapidly growing urban slums adjacent to the new factories of the Industrial Revolution.^{4,5,15,17,18} In France, the famed physician and economist Louis-René Villermé (1782-1863) conducted unprecedented empirical research demonstrating that poverty was directly associated not only with elevated mortality rates in Parisian neighborhoods, but also with short stature, illness, and deformities among young military conscripts.¹⁸⁻²¹ His explicit inference was that body size, body proportions, morbidity, and mortality, far from being fixed, bore the imprint of economic conditions and could be affected by government policies.¹⁸⁻²¹ This insight led him, despite his commitment to laissez-faire economics, to advocate the abolition of child labor, resulting in France's becoming the first modern nation to enact such a ban.¹⁸

Taking this argument a step further, Friedrich Engels (1820-1895) – in one of the era's classic texts, *The Condition of the Working Class in England*²² – vividly described how the bodies and health of destitute workers and their children were destroyed by horrific living and working conditions. At this time, the emerging liberal sanitary creed held that individual immorality and filth were responsible for the poverty and afflictions of the poor; and it assumed that moral instruction and sewers, in the absence of economic reform, were sufficient to reduce mortality.^{5,15,17} By contrast, Engels declared that the health crisis reflected the triumph of private profit over social welfare. Indeed, he wrote that the existence of government reports replete with data on societal and environmental determinants of poor health “proves that society is aware of the fact that its policy results” in disparate harm²² (p. 109) – and that government was thus guilty of “social murder.” Not surprisingly, this claim was refuted by those upholding the status quo. Ever since, a fundamental debate has raged over whether social inequalities in health are rooted in individual deficiencies or in societal injustice – with profound implications for apt remedies.^{2,5,15,19}

Hence our symposium series. We take it as a basic fact that we all live and act in bodies that literally embody – biologically, across the lifecourse – our societal and ecological context. It is from this fact of embodiment that population patterns of health, disease, and well-being arise; the causes of social inequalities in health are thus to be found in our body politic, not our innate constitution.^{18,21,23} Our symposium series extends centuries of evidence regarding government accountability for health with new insights into the hazards posed by economic deprivation, discrimination, lack of access to health services, and violation or neglect of human rights. Ultimately, it poses the question: What is it that government can – and should – do to eliminate disparities and guarantee conditions enabling a healthy life for all?

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Spreading the Health: Government's Role in Addressing Health Disparities

Madeline Drexler

Introduction:

In the last decades of the twentieth century, industrialized countries saw extraordinary economic prosperity and advances in medical science. Over the same period, the gap between rich and poor, advantaged and disadvantaged, sick and healthy, widened.

A growing body of research in the health and social sciences has underscored the link between social equity and population patterns of disease, as investigators discover new connections between "healthy bodies and thick wallets." Meanwhile, policies on the environment, transportation, labor, housing, and medical services have profoundly affected citizens' physical and mental well-being. By bridging traditional divisions within their bureaucracies, governments can construct policies that will reduce or eliminate health disparities.

Poverty, joblessness, and discrimination take a heavy toll on the human body. Yet only in the past two decades have government leaders explicitly focused on the problem of socially-determined disparities in health. What findings and insights have their first tentative steps yielded? What lessons can other administrations learn from policies specifically attuned to the social determinants of disease? How could and should national officials respond to the persistent gap between the health "haves" and "have-nots"?

On March 3, 2005, the Working Group on Health Disparities at the Harvard School of Public Health held the first of three international symposia addressing these issues. Featuring visionary public health leaders

Income and Self-Reported Health



U.S. national data showing socioeconomic gradient in self-reported health. Increasing poverty is associated with poorer self-reported health.

from Sweden, the United Kingdom, Mexico, and the United States, the symposium examined both the successes and challenges of new policy approaches. By fostering frank cross-cultural discussion, the forum also sought to inspire action on one of today's most knotty public health problems. "If I were to say what I think the role of academics should be and has been in relating to this issue," said Barry R. Bloom, Ph.D., Dean of the Harvard School of Public Health, "it's to hold governments accountable for the health of their people."

Health Disparities Today

Over the last decade, the term "social determinants of health" has gained credence. Starting in the late 1990s, several countries – including those represented in this symposium – began to design and launch policies to reduce health disparities. Regardless of locale, the problem they face remains the same: in every nation and every culture, individual health is stamped by large social forces. In the U.S., "disparities continued to be pervasive across all dimensions of care, across many levels and types of care, with almost any clinical condition, and within many subpopulations," said Carolyn Clancy, M.D., Director of the Agency for Healthcare Research and Quality (AHRQ), part of the U.S. Department of Health and Human Services.

Among Medicare beneficiaries who have suffered heart attacks, for example, 59 percent of white men who are eligible receive clot-busting drugs,

compared to 44 percent of black women. African Americans and Latinos hospitalized with a heart attack are less likely on discharge to be advised to quit smoking than are whites. Blacks admitted to the emergency room with a broken arm get 20 percent less pain medication than do whites with the same injury. In the U.S., income is inversely correlated with both arthritis and depression. And nationally, 46 percent of low-income adults eligible for government-sponsored health insurance are not enrolled in the program; most dismaying, the poorest – those with incomes less than half of the poverty line – are least likely to sign up.

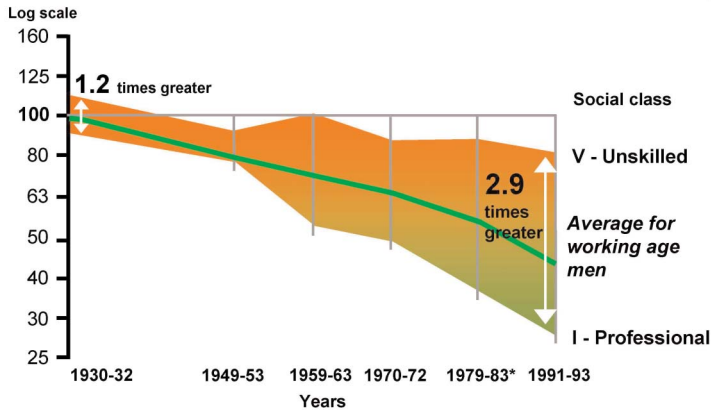


Carolyn Clancy, M.D.

The 2004 National Healthcare Disparities Report – an annual document mandated by the U.S. Congress (starting in 2003) to track “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations” – found that gaps in healthcare quality are especially acute for certain racial, ethnic, and socioeconomic groups. “Blacks and Hispanics score lower than whites in about half of the quality measures,” Clancy reported. “Hispanics and Asians score lower than whites in about two-thirds of access measures. And poor people score lower on about two-thirds of both quality and access measures.” Indeed, according to Massachusetts State Senator Dianne Wilkerson, a symposium discussant, blacks and Latinos in Boston suffer the worst health of all racial groups on 17 of 20 measures. In the shadow of some of the nation’s finest medical institutions in Harvard’s Longwood medical campus – including the high-tech conference center where the symposium was held – infant mortality among Latinos is three times greater than among white babies.

In England and Wales, the picture is also grim. “We still have totally unacceptable levels of social inequity,” said Fiona Adshead, M.D., Deputy Chief Medical Officer in the United Kingdom’s Department of Health. Since the U.K.’s National Health Service was established in the 1930s, the health gap between rich and poor has actually widened; for men of working age, mortality rates are 2.9 times greater among unskilled workers than among those in the professional class. England’s geographic health divide, which partly reflects material privilege or deprivation, is likewise dramatic.

The widening mortality gap between social classes



*1979-83 excludes 1981

England and Wales. Men of working age (varies according to year, either aged 15 or 20 to age 64 or 65)

Note: These comparisons are based on social classes I & V only.

Source: Office for National Statistics. Decennial supplements.

U.K. socioeconomic gradient in mortality among working age adults, 1930-1993. The green line shows the average age-standardized mortality rate (per 100,000) for working age men; the color spread around the green line shows range of mortality rates. Persons in “unskilled occupations” (Social Class V) suffer higher mortality rates than persons in “professional occupations” (Social Class I). The relative ratio of mortality rates of persons in Class V compared to Class I increased from 1.2 in 1930-32 to 2.9 in 1991-1993, even as the overall rate of mortality in both groups declined.

As the screen behind her flashed a patchwork map depicting male life expectancy at birth, Adshead described a graphically stark north-south divide. “If you’re born in one of those red spots in the north of England, compared to one of the nicer aqua-green spots in the southwest, your life expectancy is almost nine years less.”



Fiona Adshead, M.D.

If Friedrich Engels, the nineteenth-century political philosopher and author of *The Condition of the Working Class in England*, could have time-traveled to the twenty-first century, he would have instantly recognized the pattern.

Even in Sweden – where ill health is officially construed as “placing obstacles in the path of people’s freedom to determine their own lives” and where



Irene Nilsson Carlsson

the stated national ambition is to “Create social conditions to ensure good health, on equal terms, for the entire population” – disparities persist. “Generally speaking, Swedes are healthy people. We are among the top countries in the world,” said Irene Nilsson Carlsson, Sweden’s Director of the Division for Public Health. “Good health is a core part of good life, as we consider it. Nonetheless, we can observe ... substantial diversities in health.” Wealthier Swedes live longer

and suffer fewer afflictions than do poorer Swedes. Ethnic Swedes are healthier than immigrants – particularly refugees who escaped civil wars. And residents of the country’s more rural north consume considerably more high-fat foods and fewer fruits and vegetables than do citizens in more cosmopolitan parts of the south.

Prerequisites for Change

The nascent movement to eliminate health disparities has been fueled by both realism and idealism – realism in the sense that the unyielding statistical gaps cannot be argued away, idealism in the sense that solving the problem will depend on innovation and unprecedented commitment.

What social and political factors did the speakers cite as indispensable in solving the problem?

Unanimously, they encouraged governmental teamwork. “We try to make it as easy as possible for the other ministries to work with public health,” explained Sweden’s Carlsson. She conceded that while it is difficult for any government to construct policies that span different departments, public health – which is as directly affected by economic, education, and environmental policies as by medical care itself – requires an integrated approach. For this reason, Sweden’s public health agenda is carried out via a wide gamut of government jurisdictions, including those responsible for safe work environments, clean air and water, alcohol and tobacco sales, anti-poverty and fair housing programs, and special care for children in disadvantaged communities. “It’s been much easier to make friends with other ministries than I had expected,” Carlsson said. “We have been successful in creating a win-win situation.”

Fiona Adshead agreed that bridging traditional government boundaries is key to erasing health disparities. The U.K.'s model is based on a groundbreaking study chaired by Sir Donald Acheson. The Independent Inquiry into Inequalities in Health had been charged by Tony Blair's newly-elected Labor government with identifying policy priorities. Published in 1998, the report portrayed England as riven by health divides.

The Acheson report emphasized that government departments need to work in partnership. Such a collaborative model is not always palatable to politicians, who often want to claim sole credit for a program's success – or distance themselves from its shortcomings. In the U.K.'s collaborative scheme, "You have to share political responsibility," Adshead said. "You have to share the success. And you may also have to share in some failures."

Looming over this process is the U.K.'s Treasury, which distributes all monies and holds government departments accountable for delivering on their goals. Between mid-2001 and mid-2002, the Treasury led a Cross-Cutting Review on Health Inequalities, examining how 17 government departments and programs could be coordinated to hit targets and spend funds most effectively, with the overarching goal of diminishing the health divide. Among the cross-cutting strategies that address social determinants of health are policies aimed at early child development, substandard schools, public transportation, and run-down neighborhoods.

Success Stories

As a result of such multi-pronged initiatives, bridging the health gap is no longer a hypothetical goal. Symposium speakers attested to several real-life success stories on which to build future policies.



Asa Cristina Laurell, M.D.

In 2001, for example, Mexico City's newly-elected progressive administration boldly announced it intended to reduce health inequalities. To that end, it offered food and free health services and drugs to senior citizens, followed later by free health care and medications for uninsured residents. Over four years, the city also expanded its health budget by 45 percent by cutting superfluous spending on high government officials' perks, including a 15 percent salary reduction.

The improvements between 2000 and 2004 in municipally-sponsored medical care have been dramatic, said Asa Cristina Laurell, M.D., Secretary of Health in Mexico City. “Surgeries had gone up 65 percent. Birth deliveries at our hospitals had gone up 53 percent. Emergency care had gone up 31 percent. Hospital admissions had gone up 30 percent. X-ray studies had gone up 29 percent. Laboratory tests had gone up 14 percent. And specialty consultation had gone up 4 percent. Which means that, with a program of free care, we actually gave much better access to expensive services.”

By December 2004, of 900,000 uninsured families eligible for the free care program, 710,000 had enrolled. Those most apt to sign up for the free health care program had lower incomes and less formal education, and tended to reside in poor neighborhoods. “We made an estimate of the medical expense savings for the beneficiaries over one year,” said Laurell, “and it was about \$170 million – which is an important savings for Mexican families. It means that they can dedicate their scarce resources to other kinds of social necessities.”



Impact of the Mexico City health reforms: between 2000 and 2004, access to health services improved by more than 30% for needed hospitalizations and emergency care, and by more than 50% for birth deliveries and surgeries.

The most astonishing effect was, literally, on life and death. “The standardized mortality rate is actually decreasing in Mexico City,” Laurell explained, “while it is increasing on the national level. We have been able to bring down mortality rates in practically all age groups. And we have decreased inequality between richer and poorer regions of the city.”

The United Kingdom offers a very different, though equally practical, lesson. “Sometimes progress comes in unexpected quarters,” said Fiona Adshead. One city targeted people from economically deprived groups who had been diagnosed with heart disease. The project’s goal was secondary prevention: averting in patients with established heart disease a serious medical event, such as a heart attack or stroke. “These patients wouldn’t normally have been receiving services. But the health service went out of its way to target them and make sure they got effective secondary prevention,” said Adshead. “In a period of a year, the mortality rate in that city dropped in the most deprived areas – much faster than in the more affluent areas.”

Adshead hopes to advertise that success story to persuade leaders that public health interventions can, at times, bring swift results. In the same vein, the U.K. in 2002 set an ambitious national target: to reduce by 2010 inequalities in infant mortality and life expectancy at birth by 10 percent. To achieve this goal, the government will launch initiatives to reduce smoking, improve diets, boost physical activity, prevent teen pregnancy, and improve housing conditions in disadvantaged areas.



(seated left to right): State Senator Dianne Wilkerson, Sofia Gruskin, J.D., M.I.A., Ashish Jha, M.D., M.P.H., Kalahn Taylor-Clark, M.P.H.; (standing): Deborah Prothrow-Stith, M.D.

In most cases, however, narrowing the national health gap requires years or even decades. This means that politicians must, uncharacteristically, take the long view. “In a political culture, when you need to deliver results immediately, it’s very tricky to be responsible for public health,” Sweden’s Carlsson lamented. Added Boston’s Dianne Wilkerson, “For those of us in the business of politics, where the bottom line sometimes rules, we don’t have the pleasure and the luxury of talking about prevention because we seem to get focused in the here and now.” Health disparities cast a long shadow, but they are rarely headline news.

The Social Determinants of Health Model

More than 150 years ago, the German pathologist and political reformer Rudolf Virchow observed: “Do we not always find the diseases of the populace traceable to defects in society?” Hovering over the symposium proceedings was the tacit understanding that, in order to talk about gaps in health, it is necessary to confront the social structures that guarantee those inequalities.

Since the late 1990s, Swedish public health policy has proudly anchored itself in the health determinants model. Rather than defining its objectives in terms of morbidity and mortality figures, it targets the social and environmental underpinnings of disease. The policy assumes that the government’s responsibility is to set the conditions for good health, while the individual’s is to follow up with wholesome behaviors. Its 11 domains of objectives reflect the most important influences on health, from structural factors such as economic security and educational opportunities to lifestyle choices such as good eating habits and regular physical activity.

Similarly, in Mexico City – which has one of the most lopsided income distributions in the world – health is framed as a government-guaranteed right. “The principle behind our project is that we need to democratize health, which means reducing inequalities in health indices and in access to services,” said Asa Cristina Laurell. In order to achieve this, the city bolstered its health care facilities, which had long been weakened by underfinancing, corruption, and demoralized staffs. “If you don’t have strong public institutions,” Laurell said, “it’s very difficult to grant equal and universal access.”

Indeed, universal access to quality health care was another theme that united the symposium’s speakers. In Mexico, “It’s almost taken for granted that health is an important form of social justice,” said Laurell, adding that

citizens are more willing to pay for universal care than for programs that target special groups.

Carolyn Clancy also argued for universal access to quality care, but from the paradoxical vantage point of the American health system. Though the U.S. boasts of having the world's best medical care, Americans in fact receive recommended treatment only 54.9 percent of the time. "We have big-time quality of care problems overall for everyone," Clancy said. Predictably, those who receive the worst care of all are members of racial or ethnic minorities, people in lower socioeconomic positions, and individuals who live in rural areas. That is why, in Congressionally-mandated annual reports on health disparities, required since 2003, the Agency for Healthcare Research and Quality releases separate but related publications on healthcare quality and healthcare disparities. Since about half of Americans receive substandard treatment, Clancy's vision of universal access to quality care has a slightly different twist. For her, the disparities are not only between privileged and deprived patients – but, just as important, between evidence-based healthcare and less-than-optimal treatment.

Charting the Future

In the unfolding campaign to reduce health disparities, where should government policies be pointing?

Leaders are bound to deploy the argument that eliminating disparities saves money. A recent study in *Health Affairs* predicts that, by 2014, governments in the U.S. will assume 50 percent of national health care expenditures. That trend is mirrored in other countries. "If we don't act on some of the major health issues – obesity, sexual health, smoking, substance misuse – then, in fact, the amount that we have to spend on health care will be superseded by the amount we need to spend on health," said the U.K.'s Fiona Adshead.

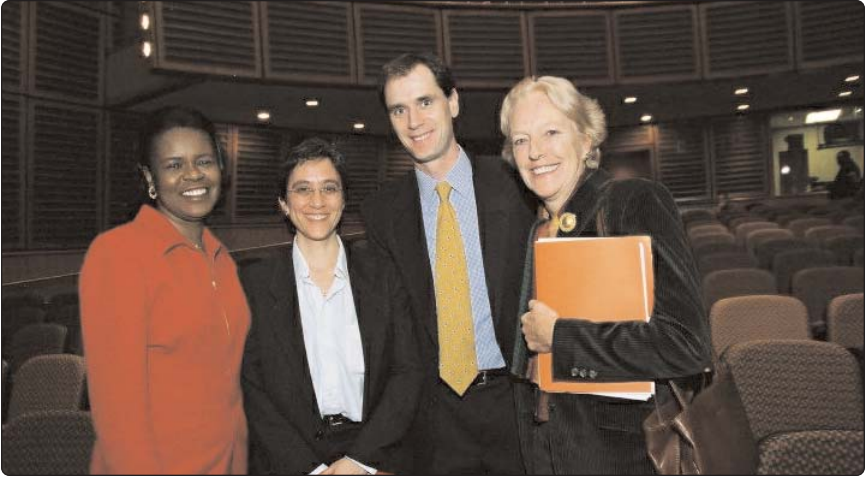
In the U.S., private companies are also feeling the financial pinch of disparities and are beginning to ask: If we pay the same insurance premiums for all of our employees, why are some workers getting better care than others? According to Clancy, that concern may put the private sector out front on the issue. "Leaders from nine health plans came to us and said, 'We know we have a problem. We don't even have data and we know we have a problem. We need your help, we need your technical assistance,'" she said. Out of the companies' concerns has grown the National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality, a public/private partnership that will focus on reducing gaps in health care for

people with diabetes and other conditions. Only 32 percent of Americans with diabetes receive recommended services; the figure is even lower for African Americans, Hispanics, and Native Americans. Over the next three years, the collaborative will test ways to improve data collection on race and ethnicity and match these data to existing quality of care measures. Ultimately, the collaborative seeks to fashion interventions that will wipe out inequities in care and that can be replicated by other insurers such as Medicare and Medicaid.

Yet governments cannot leave health disparities for the private sector to solve. According to Sweden's Carlsson, national administrations must keep an unwavering focus on health determinants, rather than on discrete diseases. While constituency groups for particular diseases may garner popular support, they do not solve the underlying conditions that give rise to the vast majority of human afflictions. "I cannot see a more efficient alternative to public health policy than to struggle with health determinants," Carlsson said. "Last year, the EU launched a strategy to combat heart and coronary diseases. But we succeeded in arguing that this strategy should be based on a health determinant perspective. We have to be reminded that dealing with public health is essentially a matter of preventing and promoting, not treating and curing."

Beyond wrestling with societal determinants, researchers also need to tease out the individual factors behind broad health disparities. As Adshead sees it, living in a consumer society has encouraged people to expect endless variety and choice – even in their health options. In a sense, public health officials need to sell their message as persuasively as savvy marketers sell sneakers or cell phones. "We all expect things to be about us, the way we live our lives," Adshead said. "We need to think about how to personalize health advice ... so that people really want to improve their eating or stop smoking."

Some citizens, unfortunately, have fewer choices than others. People in lower socioeconomic groups typically feel less control over their lives – and over their health. Carlsson pointed out that low-income individuals often lack not only education and economic resources, but time. "The lack of time is very important," she stressed. "It is often easier to make an unhealthy choice than a healthy one. A frightening observation is that for some poor women, the only time they could rest is when they lit a cigarette." So it is no surprise that Sweden's public health agenda focuses on quality of life as much as quality of care.



(left to right): State Senator Dianne Wilkerson, Nancy Krieger, Ph.D., David Studdert, L.L.B., Sc.D., Asa Cristina Laurell, M.D.

In the end, governments must plunge into action, even if they do not have all the answers. Many contentious issues, both practical and theoretical, remain. What proportion of disparities in health are due to healthcare alone? What proportion are due to physical environment, social and economic pressures, or lifestyle? How can public health more effectively sell its promotion and prevention message? Should citizens be compelled to adopt healthy behaviors? Do egalitarian societies exhibit better health than non-egalitarian societies? And how should governments address what Britain's Acheson report made clear was not a simple rich-poor divide, but a social gradient in which inequalities persist all along the health-wealth continuum?

"We are all struggling with a common challenge, which is: How do we make a dent?" said Clancy. "We know how to report and describe – we're really good at that. How do we transform that into action and evaluate the effectiveness?"

"We can't wait for perfect evidence," added Fiona Adshead. "The key thing on inequalities is that people tend to put it into the 'too difficult' box. To politicians, it just seems too complicated. By the time you realized that the whole of government policy is needed in order to improve this problem, you don't want to get out of bed to solve it."

But, she said, there's no time to lose. "Let's just do something Whoever carries the flame – whether it's in the academic community, in the policy forum, or because of political will and momentum – it must be taken forward."

Carolyn Clancy may have best summed up the hopes and dilemmas of public health officials confronting the tangled causes of health disparities: "Do we know enough to intervene? No. But we have to."

Symposium participants:

Moderator:

David Studdert, L.L.B., Sc.D., Associate Professor of Law and Public Health, Harvard School of Public Health (HSPH)

Speakers:

Carolyn Clancy, M.D., Director, Agency for Healthcare Research and Quality, United States Department of Health and Human Services

Fiona Adshead, M.D., Deputy Chief Medical Officer, Department of Health, England, United Kingdom

Asa Cristina Laurell, M.D., Minister of Health, Mexico City

Irene Nilsson Carlsson, Director, Division for Public Health, Sweden

Discussant:

Dianne Wilkerson, Massachusetts State Senate

Q & A Panel:

Deborah Prothrow-Stith, M.D., Professor of Public Health Practice, HSPH, Facilitator

Kalahn Taylor-Clark, M.P.H., W.K. Kellogg Doctoral Fellow in Health Policy Research, Harvard University

Sofia Gruskin, J.D., M.I.A., Associate Professor of Health and Human Rights, HSPH

Ashish Jha, M.D., M.P.H., Assistant Professor of Health Management, HSPH, and Harvard Medical School Research Fellow in Medicine

Investigating Health Disparities: New Agendas for National Health Research Institutes

Madeline Drexler

Introduction:

Observers have commented upon social disparities in health for centuries. But not until recently have these gaps received rigorous research attention or dedicated funding among national health institutes.

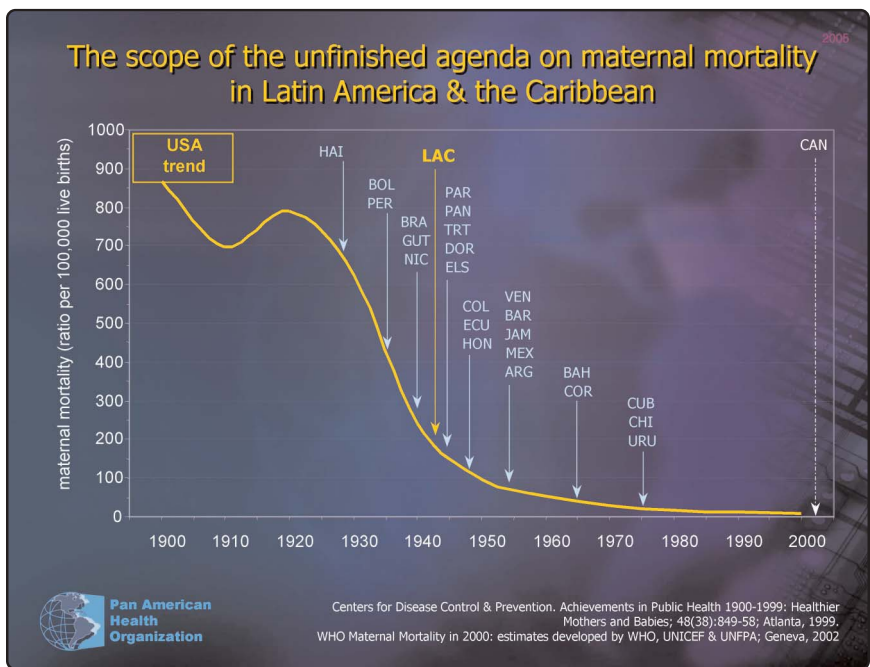
To improve the health of disadvantaged populations, governments need solid data about the magnitude of the problem and the fundamental causes of disparities. Understanding the complex interactions among social networks, physical environment, health care access, personal behaviors, and biological vulnerability, in turn, requires thoughtful planning across research institutes. Yet because the roots of health disparities are intertwined, building a national health research institutes agenda and the infrastructure to support it is a formidable task.

In Haiti, mothers die in childbirth at the same rate today that they did in the United States in 1930. In the sprawling country of India, the two most historically outcast groups – the Dalits and the Adivasi – bear a disproportionate burden of disease, from TB to asthma to leprosy. In Canada, 62 percent of First Nations and Inuit citizens smoke – compared to 31 percent of the rest of the population. In the United States, blacks die of stroke at higher rates and at a younger age than whites.

What accounts for these stark differences? How can health officials leverage scientific data to dissolve such inequalities? More broadly, how should governments organize and fund national health research in order to address the tragically divergent life paths of their citizens?

On April 14, 2005, the second of three international symposia organized by the Working Group on Health Disparities at the Harvard School of Public Health examined how governments are expanding their research missions to grapple with health inequities. Participants included policymakers from India, Canada, the United States, and the Pan American Health Organization (PAHO).

What we now term “health disparities” – the consistent gap in physical and mental well-being between the most privileged people in society and the most socially and economically disadvantaged – launched the modern public health movement in the nineteenth century. Then and now, recognizing and eliminating these inequalities have been at the heart of the public health mission. Yet teasing apart the causes of disparities remains an elusive goal.

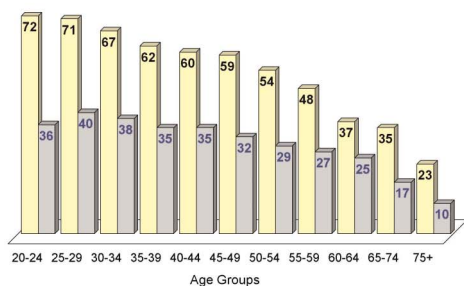


Orange line represents U.S. maternal mortality rate by calendar year, from 1900 to 2000. Arrows illustrate how current (2000) maternal mortality rates in Latin American and Caribbean countries (identified by abbreviation) correspond to U.S. maternal mortality rates in earlier time periods.

Smoking Rates

by Age Group and Ethnicity

First Nations/Inuit Smoking Rates versus Canadian* Smoking Rates, by Age Group



- First Nations and Labrador Inuit - 62% overall: Canadian counterparts - 31%.
- First Nations and Inuit 20-24 age category - 72%.

FNIRHS data based on population expansion weighted proportion, 1997
 * Source= National Population Health Survey, 1994-95

Canadian data on racial/ethnic disparities in smoking rates (1994-1995), showing a two-fold greater prevalence of smoking among First Nation and Inuit compared to the rest of Canadians. Absolute difference in prevalence rates is greatest at younger ages, when smoking is most common.

Entering the public health profession, investigators are admonished never to settle for anything less than “root causes.” But what are the root causes of a phenomenon so deep and intractable: Poverty? Lack of education? Ingrained cultural beliefs? Social prejudice? Substandard medical care? Myopic government policies?

The terrain is staggeringly wide. “We’ve often thought about health disparities as off the charts for real scientific investigation,” said Lisa Berkman, Ph.D., chair of the Department of Society, Human Development and Health at the Harvard School of Public Health. “People have said this is the ‘mushy’ part, the ‘fuzzy’ part, the part that nobody knows how to measure.”

“When I started to address this issue ... I had total confidence that we could solve the problem,” added Elias A. Zerhouni, M.D., director of the U.S. National Institutes of Health. “I still do –



John Frank, M.D. and Lisa Berkman, Ph.D.

in the definition of ‘confidence’ that I know: the feeling you have before you understand the problem.”

The problem is that the forces molding disparities are part of a matrix of physical and cultural influences. “People go from womb to tomb, not in random space and time, but inside nested human societal substructures,” explained John Frank, M.D., scientific director of the Institute of Population and Public Health, part of the Canadian Institutes of Health Research. Disparities spring from such varied factors as biology, genetics, family upbringing, neighborhoods, school, work, income, toxic exposures, social networks, access to health care, national economic policies, and even globalization.

Which of these exert the most profound effects over populations? According to Berkman, “If we don’t get the scientific questions right, we can’t hope to design successful interventions. For instance, if we thought that early life exposures shape subsequent health outcomes throughout the whole life course, it points toward early intervention. If it turns out that it isn’t early time periods that are important, but rather cumulative disadvantage across the life course, then we have many opportunities to intervene.”

The answers to such scientific puzzles will ultimately guide government investment. “Countries are asking: How do we know where to put our money in order to reduce disparities?” said Mirta Roses Periago, M.D., M.P.H., director of PAHO.

But research into health inequalities also raises ethical issues. “When we think about disparities, it’s important to be explicit about the question: Why do we care about them?” asked Harvey V. Fineberg, M.D., Ph.D., president of the Institute of Medicine. “One approach would say that disparities in health outcomes are important because they provide us a lens on understanding the causes of health. A second notion would be that disparities matter because we believe that equity itself is a contributor to health. A third point of view says that we care about disparities in health because they



Harvey V. Fineberg, M.D., Ph.D.

actually affect many things beyond health, such as economic opportunity. And a fourth reason that we might care is that the presence of disparities offends our sense of social justice.

“All of this is not in any way to diminish a direct concern for the health needs of the poor or the disadvantaged. But disparities *per se* offend us as a society. Offend our sense of who we are and what we want to be.”

As Barry R. Bloom, Ph.D., Dean of the Harvard School of Public Health, summed it up, health disparities “perturb the consciences of people within the country and around the world.”

Health Disparities Today

Health disparities are astonishingly consistent – within and between nations. “We have seen disparities across economic, social, racial, and ethnic backgrounds in almost every country for almost as long as we have measured them,” said Berkman. A groundbreaking method of gauging health disparities across populations was developed in the early 1990s by the Burden of Disease Unit, co-led by Christopher J. L. Murray, D.Phil., M.D., now director of the Harvard Initiative for Global Health. In 1999, data from 191 nations revealed a staggering divide in life expectancy between the highest and lowest rated countries. In Japan, life expectancy at birth for women was 84.3 years; in Sierra Leone, the figure for men was 33.2 years.

Yet the specifics of health disparities range widely. In one country, they may be expressed in terms of infection rates; in another, cardiovascular diseases or cancer. Even the axiom that health follows wealth shifts with locale; the classic inverse correlation between income and mortality rates changes its profile across nations. At the same time, the relationship between income inequality at the city or state level looks dramatically different from country to country. Studies show a strong direct association between income inequality and all-cause adult mortality in the U.S. and the United Kingdom, for example, but no clear correlations in Sweden, Australia, and Canada. “So it is not a universal relationship,” said Frank. “It’s contextualized by culture, policies, and history.”

National Profiles

With a population of 1 billion, 14 national languages, 6,000 dialects, and every conceivable religious denomination, India represents a vast tapestry of cultures, each with its own norms and health behaviors. It also represents a textbook example of health disparities. The western state of Kerala compares favorably to any modern market economy, in measures ranging from

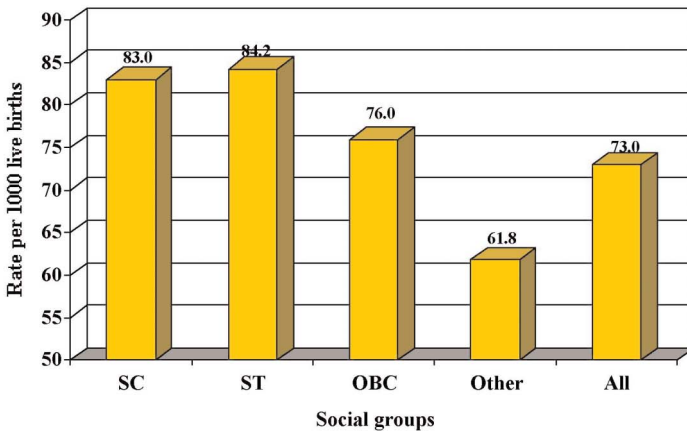


K. Sujatha Rao, I.A.S.

maternal and infant mortality to literacy. By contrast, life in the nation's northern belt – the so-called “lagging states” – is far more precarious. Much of India's disease burden is borne by the groups administratively labeled “Scheduled Castes” (formerly known as “untouchables” or Dalits) and “Scheduled Tribes” (aboriginal groups known as Adivasi).

In these societies, infant mortality (IMR) and maternal mortality outstrip those of any other group because of poor access to health services and unsafe deliveries. Malnutrition and anemia are far more common among the poor. In some parts of the country, female infanticide and deprivation have led to higher mortality rates in girls under five.

INFANT MORTALITY RATES BY SOCIAL GROUPS IN INDIA



In India, overall infant mortality rate is a composite measure of the infant mortality rates in various social groups. Infant mortality rates are highest in “Scheduled Castes” (SC) and “Scheduled Tribes” (ST), followed by groups termed “Other Backward Castes” (OBC) and all “Others.” Latter group represents more affluent sectors of Indian society.

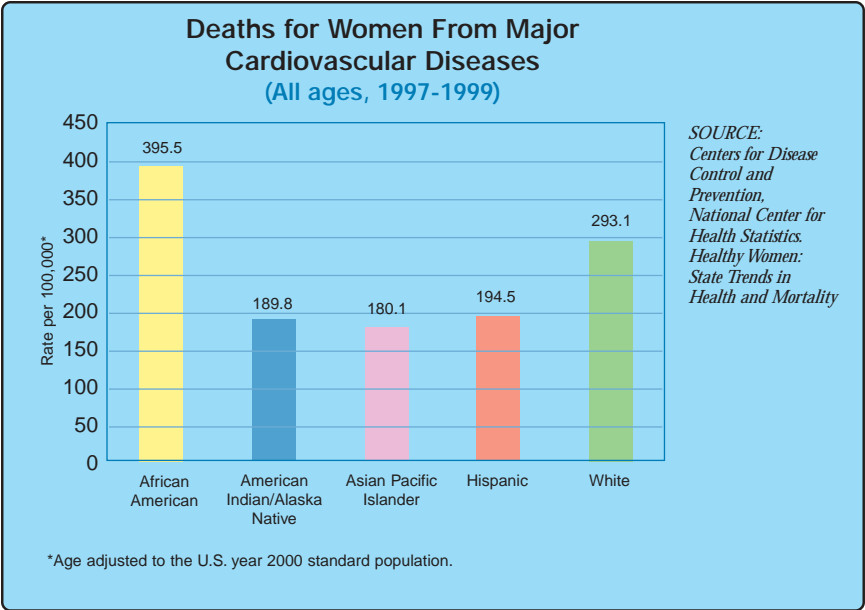
“Normally, it is felt that the poor only suffer from communicable diseases and not necessarily lifestyle diseases,” said K. Sujatha Rao, I.A.S., secretary of India’s National Commission on Macroeconomics and Health. “But today we find evidence emerging that the poor are also suffering from diseases like asthma, hypertension, diabetes – and we don’t have a public policy response to the non-communicable diseases.”

In India, disparities also crop up in access to medical services. Public health clinics are less geographically dispersed than private medical facilities. Moreover, said Rao, “The payment system in our country is still on fee for service, at the point of service, which means if you don’t have money you don’t get care.” The financial binds are especially tight in rural areas, which are more impoverished. “Forty percent of people who get into a hospital have to sell their assets or borrow money at usurious interest rates,” said Rao. “Intergenerational poverty sets in because once you sell your assets or are in deep debt, it means pulling the kids out of school, making them earn for the family. That has its own intergenerational impact, and it cycles on and on.”

In Latin America, recent health gains are under threat. “We are looking at widening disparities and a rising exclusion from the health system,” explained Roses Periago. While life expectancy in the region has risen six years over the past quarter century, the economic gap between rich and poor – as expressed in average gross national product per capita, as well as in per capita income – has widened. Some nations, such as Haiti, have remained mired in wretched health conditions. Indeed, Haiti is the only country in the region with a life expectancy below 60 years.

In the U.S., where inequalities in wealth have exploded, health inequalities have followed. A 1998 investigation, titled the U.S. Burden of Disease and Injury, made this chasm graphically clear. For instance, life expectancy for American Indians and Alaskan Native males in several South Dakota counties was 41.3 years less than life expectancy for female Asian and Pacific Islanders in parts of New Jersey – the most gaping county disparity in the U.S., and one that mirrors the international divide in life expectancy between Sierra Leone and Japan.

According to Director Elias Zerhouni, the NIH is taking a close look at the diseases that underlie those breathtaking differences. In the U.S., obesity disproportionately affects African Americans and Latinos. Death from cardiovascular disease is more prevalent in African Americans than in any other group. Older African Americans suffering from lung cancer receive less



U.S. data on racial/ethnic disparities for cardiovascular mortality among women (1997-1999), showing highest rates among African-American women.

surgery and have a lower resulting survival rate for the disease, compared to whites – perhaps due to late detection. Since the mid-1980s, incidence rates of kidney cancer for both black men and women have exceeded the rates for their white counterparts. Even Sudden Infant Death Syndrome strikes African-American babies at higher rates than it does babies from any other groups.

In Canada, a longitudinal analysis linking career earnings with all-cause mortality tells a similar story. The massive 1993 study followed thousands of Canadian pension plan payees into the first five years of retirement. “Guess what? You think we live in an egalitarian society? Think again,” said John Frank. “Twice as many deaths in people in the lowest decile of income over their last two decades of working life, compared to the top decile.”

Efforts to Reduce Disparities

Such statistics have stirred governments and NGOs into action. In 1977, the United Nation’s World Health Assembly ambitiously declared “Health for All” by the year 2000, so that citizens everywhere could lead socially and economically productive lives. The results have been mixed; while many developing nations have seen improvements in immunization coverage,

trained attendance at childbirth, and local health services, they have also witnessed high maternal mortality rates and the relentless spread of both infectious and chronic afflictions. In 2000, at the United Nations Millennium Summit, world leaders agreed to time-bound and measurable goals to combat disease, poverty, and hunger. Among the specific targets were child and maternal mortality, HIV/AIDS, malaria, and other scourges. The World Health Organization's Commission on Social Determinants of Health, which began operations in 2005, is also turning existing public health knowledge into practical goals and national policy agendas.

In the U.S., the NIH – embracing 27 different institutes and centers – is tackling disparities in a multidisciplinary campaign. Its health disparities initiative is one of five priority areas of investigation for the agency. Health disparities are being studied as part of the NIH Roadmap for Medical Research. “The Roadmap was our first attempt at looking across the NIH at areas where no single institute could address the issues, but all of NIH needed to,” said Zerhouni. “Health disparities qualifies, hands down, as one of those issues.”



Elias A. Zerhouni, M.D.

The 2004 Health Disparities Strategic Plan is coordinated by the National Center for Minority Health and Health Disparities. According to the plan, each institute and center determines its health disparities goals, while following the framework of NIH's overall plan. That plan's mission is

simple, said Zerhouni: “to promote minority health, coordinate support, and assess the NIH effort to reduce and ultimately eliminate health disparities.” In the 2006 fiscal year, the Center's budget is expected to approach \$200 million – or just under .7 percent of the total NIH budget.

NIH's disparities research is necessarily broad-based. Among its efforts are attempts to identify barriers to health care access; examine race and long-term diabetes self-management in an HMO; compare mutations in the androgen receptor gene among African American and white women with breast cancer – to study the role of genetic susceptibility; and reduce HIV and STD infections in young adult minority populations.

In 2003, the NIH launched eight Centers for Population Health and Health

Disparities to support cutting-edge research in outcomes, access and care. The Center to Reduce Cancer Health Disparities, funded by the National Cancer Institute, is tracking more than 2,800 research projects. According to Zerhouni, “It’s not a meta-analysis, but a functional analysis of what research is being undertaken and funded by NIH within different communities, trying to extract strategic information from that investment.”

The National Heart, Lung, and Blood Institute has staged a major experiment in the southern state of Mississippi with the ongoing Jackson Heart Study. Researchers are investigating heart disease, stroke, and diabetes in African Americans, with the aim of learning how to best prevent these conditions.

A landmark study known as ALLHAT – the Antihypertensive and Lipid-Lowering Treatment to Prevent Heart Attack Trial – also zeroes in on health disparities. The largest clinical trial of hypertension ever conducted, it has enrolled more than 42,000 participants – 35 percent of whom are African American – across the southern and rural “stroke belt” of the United States. Among the study’s questions: Are physicians treating these populations properly for hypertension? Five drugs were tested. “It turns out that the least expensive drug – diuretics that have been around for a long time – were the most effective as a first attempt to reduce blood pressure,” said Zerhouni. “And it turns out to be even more effective in African Americans, compared to more expensive brand name drugs.” Another encouraging discovery: compliance rates for taking these medications remained high in the populations tested, even after the trial had ended. To Zerhouni, this shows that when disparities research is thoughtfully integrated into the communities under study, “you have follow-on effects or halo effects, which over time might be cumulative.”

NIH’s disparities work has also reached across national borders, since the very same ethnic groups can have markedly different patterns of disease, depending on where they reside. The National Institute of Diabetes and Digestive and Kidney Diseases, for example, has sponsored a study of diabetes risk factors in Pima Indians living in southern Mexico and in Arizona, examining diet, exercise, and other behaviors in these genetically identical populations. The investigation revealed that Pima Indians in the U.S. – who are more prone to diabetes – consumed a diet that was 40 percent fat and high in processed foods, and that they exercised infrequently. By contrast, the Pima Indians in Mexico ate a 15 percent fat diet, with lots of unprocessed foods and high fiber. The NIH is further studying a gene on

Chromosome 1 linked to fat metabolism, hoping to account for the higher diabetes vulnerability in the Arizona tribe members.

One of the most visionary national programs is the Canadian Institutes of Health Research, established in 2000. Among the 13 institutes are those of Aboriginal Peoples' Health, of Gender and Health, and of Population and Public Health (the latter directed by John Frank). "These are statements about values. They suggest the need for research to be responsive to major social problems," said Frank. "We may not be able to change your genes right away, but we can do something about your context." Mindful of the diverse forces behind health disparities, these institutes invest primarily in interdisciplinary research teams and often require scientists to forge partnerships with community groups and policymakers.

Despite its lofty mandate, the Institute of Population and Public Health is not munificently funded. "The good news is that we get to cover everything," said Frank – that is, everything the U.S. Centers for Disease Control and Prevention cover; everything the National Institute for Occupational Safety and Health and the National Institute of Environmental Health Sciences cover; everything all the epidemiological and social/behavioral science panels at NIH cover. "The bad news is that I have only about \$8 million Canadian a year to spend."

Within the 38 member nations of the Pan American Health Organization, reducing health disparities has meant making "tough but very courageous decisions," explained Director Mirta Roses Periago. One of those decisions was designating high-risk nations that would receive extra funding. "Now the priority countries have been named – which is something politicians usually avoid," she said. "They are Haiti, Guyana, Bolivia, Nicaragua, and Honduras." By singling out these nations as deserving of special allocations, Roses Periago proudly noted, PAHO distributed funds strictly according to the principles of equity.

In India, the prospect of tapping into the modern equipment and specialized medical skills of the private health care network has piqued the interest of policymakers. "We have a huge private



Mirta Roses Periago, M.D., M.P.H.

health system in our country, which has grown over the last 20 years relative to the public system,” said K. Sujatha Rao. The private system possesses advanced technology and an array of experts who specialize in treating chronic illnesses such as hypertension, diabetes, and cardiac diseases – conditions that are increasingly striking the poor. “We are beginning to realize that if the government could engage with the private sector” – with policies that shield the facilities from financial and insurance risk – “we have a huge resource which could help us achieve our public health goals.”

Research Challenges

Skillful government intervention depends on strong scientific evidence and a corps of committed researchers. But as the symposium’s speakers attested, those necessities are in short supply.

Often, officials must rely on spotty or inadequate data. “As a policymaker, I want to say: What is the quality of research? What should I know? What don’t I know? And what is it that I ought to know?” said Rao. But in India, she and her colleagues lack sound estimates of the prevalence and incidence of various diseases. They do not know what health measures poorer citizens actually want – from bed nets to condoms to state-of-the-art TB treatment. And they do not have a good picture of women’s health concerns, largely because most researchers are men.

Rao seldom has access to the most up-to-date studies in the field. As in many developing countries, “the interface between government policymakers and academic researchers is not automatic – in fact, it isn’t there. The researchers are in their own watertight compartments, picking up whatever they want to do research on. They do an awful lot of good work, but it never gets to the policymaker. Very often, policies are made without much evidence. Only much later, in hindsight, after health officials made mistakes, do we say, ‘Where was the evidence and why did we go into this at all?’”

Complicating matters, whatever data do exist are difficult to track down. When Rao attempted to find out how much money the government spent on health, it meant contacting 240 public sector units, 8,000 government offices, and 10,000 budget directors. “Getting any information in India is truly heroic,” she said. “There is very little transparency. The government is cautious on sharing data. We need to let data out – we need to encourage researchers to look at it, critique it, and tell us back again where we went wrong. Otherwise, it’s impossible for us to achieve any kind of minimal health goals.”

For different reasons, obtaining the proper data to illuminate disparities in the U.S. is also becoming burdensome. Shifting administrative definitions of race and ethnicity, privacy concerns, and state laws that erase the concept of ethnic or racial or gender disparities have undermined the statistical database. “As we go forward,” Zerhouni said, “it’s going to be harder and harder, without a better epidemiological system, to capture the essence of the disparities that we’re looking at.”

Even in Canada, data gaps skewed the widely-cited 1993 study linking income with mortality in pensioners. The respondents were all stably employed, all pensionable – and all men. “We couldn’t do the record linkage when married women changed their names,” Frank explained. “Typical, eh? Sexism frames the way research can and cannot study questions.”

Recruiting and sustaining researchers in an unsung discipline is also a daunting task. “We need to make specific investments to encourage scientists to go into the field,” said Zerhouni. To that end, the NIH has funded the Health Disparities Research Loan Repayment Program (one of five NIH loan repayment programs), to attract scientists of all races and ethnicities for clinical or behavioral studies. So far, NIH has funded 466 investigators in 42 states and the District of Columbia; 56 percent of those researchers are themselves members of a health disparity population. Dispatching men and women to study their own cultures strengthens the “spiritual-emotional connection,” in Zerhouni’s words, between scientists and their often-isolated subjects. “There are intangible cultural factors that can only be crossed by members of the same community,” he said.

But in other respects, engaging scientists from disparity populations has fallen short. According to Zerhouni, only three Native American scientists are involved in NIH disparities studies – perhaps because of socioeconomic or educational hurdles. “We are failing to provide educational pathways for the children in those communities to have research careers,” he explained. “I’ve visited Haskell University, which is one of the two federally-funded American Indian universities to develop to a high level. You see the facilities there, the support, the infrastructure – and you realize that the investment should have been made earlier. By the time they get to Haskell University, the game is over.”

Cultivating new researchers is also constrained by the hidebound traditions of academia. “In Canada,” said Frank, “we have terrible disparities in capacity: In Atlantic Canada, the prairies, the north, it’s a tremendous

challenge to train people who will work there and stay there.” He blamed the situation partly on the reluctance of non-tenured researchers to become involved in community activism. “Too risky. Get involved in community groups – never get the papers published.” Modern scientific research, Frank lamented, is more about “academic impact” – grants and publications and citations – than about “impact in the world.”

Aspiring Latin American researchers likewise feel frustrated. According to Roses Periago, when northern research institutes or universities recruit scientists from the southern hemisphere, they bring them to work on health problems of the north – not on problems plaguing the scientists’ native countries. “We have to close that research gap in Latin America,” she said.

Two Mindsets: Medical vs. Public Health

Scientists working to solve health disparities must also wrestle with a deeper philosophical contradiction: between a mindset that focuses on disease and prizes medical cures, and a mindset that looks holistically at societal factors and tries to prevent illness from occurring in the first place. “We’ve had enormous success and public support for funding of research by disease, but we’ve not seen in any of the countries that have been represented here the same success or priority for the public health model of research,” said Atul Gawande, M.D., a physician and author and founder of the Center for Surgery and Public Health.

Director Roses Periago agreed. Most health problems, she noted, stem from broad social conditions – the “causes behind the causes” of ill health: poverty, social exclusion, poor housing, hazards in early childhood, unsafe working conditions, inadequate health systems, and stigma and discrimination.

As Rao sees it, “verticalized” and “techno-managerial” disease control programs in poor nations have sowed as many problems as solutions. “Donors who give money want to know where that money is going. It’s very risky to just say that the money was given for health system improvement. They want to know, ‘If we are giving you money for malaria, has malaria come down?’ You give a whole lot of money to try to eradicate polio, but what happens to the rest of the vaccine-preventable diseases?” she asked. “It’s as if to say people only suffer from A, B, C, D diseases, based on a prioritized scale. My argument has been that if we set the health system right, the disease control programs will also get addressed.”

Maybe the problem, Gawande conjectured, is that while special interest



(left to right) Atul Gawande, M.D., Judyann Bigby, M.D., Maria Glymour, Sc.D., Harvey V. Fineberg, M.D., Ph.D.

groups have formed to battle individual diseases, there are no advocacy organizations – and no public honors – for fighting health disparities. “Perhaps it’s that the researchers are not excited: there is no Nobel Prize for saving the most lives.” Or, he added, maybe politics and profits are inherently at odds. “If income and cholesterol both have

powerful effects on coronary artery disease, there’s a statin that will be funded by industry. But raising income sounds political, and that keeps everybody away.”

The medical mindset permeates all cultures – rich and poor – as an anecdote from John Frank illustrated: “In aboriginal First Nations communities in Canada, youth suicide is endemic and periodically epidemic. Something like 300 teenagers have committed suicide successfully in Ontario alone.” Most researchers assumed the problem centered in the individual torment of each victim. But the most compelling explanation was offered by a pair of social psychologists. According to Frank, their studies found that the most powerful single predictor of youth suicide in native communities is lack of cultural continuity and self-determination, including economic self-determination. “In other words, the root cause of this problem, while explicable in Western psychiatric terms, is anomie at the level of a whole community. If a community suffers anomie, the youth kill themselves.”

Solutions

What are the solutions to health disparities: Altering social determinants? Improving health care? Changing individual behaviors? Conquering disease itself?

Harvey Fineberg’s concluding remarks suggested that the question opens up many other questions – just as disparity itself enfolds countless interlocking causes:

“Do we think that we will make progress by scientific understanding and

technologic advance – because the genetic polymorphisms in cancer can be understood and compensated with treatment? Because technology that produces cheaper interventions can bring the benefits of disease prevention around the world?

“Will reducing disparities come from improving the health care system? Can we organize a reimbursement system that emphasizes preventive care? Can we provide insurance coverage to the poorest, who will then have access to services and overcome the disadvantage they may have otherwise? In other words, is organizational change and resource investment and educational improvement in the health system the key to reducing disparities?”

“Or does the key reside in intervention outside, around, before, and after the health care system? Does it have roots in a society that may have the burden of a caste history or a racism history or wide disparities in economic background? Is education the key? Is economic opportunity at the heart of improving disparities? Can we put in place the legal structures that will give every individual basic rights, protect people against discrimination, and enable them to reach and fulfill their full potential?”

Ultimately, nations and international groups must face up to the mammoth challenge of health disparities – and act. Zerhouni described a meeting in which he and other administrators were discussing how scientists could influence policymakers. He made what unwittingly turned out to be a provocative comment: That the health agenda will change when leaders are elected, not based on economic indicators such as employment or inflation, but on whether they enacted programs that helped all citizens become healthy – equally healthy. “If those things can be in the voting booth, democracies would change,” he said. “And that day is not that far off, because the burden of health care and health disparities on the system is going to be so high that there is no way a political entity could survive without addressing the issue head on.”

Roses Periago seconded the call for scientific evidence paired with political accountability. “Is this a problem of knowledge or a problem of power?” she asked. Both, she concluded.

As Harvey Fineberg told the gathering, “At heart, whenever you look at disparities, if you aren’t motivated by a fundamental sense of injustice, there’s no motivation. Because the question then is: ‘So what? So some people die sooner than others? The most important epidemiologic fact is that everybody is going die once.’”

“You have to have a sense of moral outrage at the fact that there are individuals in our society – based on irrelevant attributes, relative to their rights to health – who suffer and die prematurely. If you don’t feel that, then the rest of the discussion is totally academic, and largely irrelevant.”

Symposium participants:

Moderator:

Lisa Berkman, Ph.D., Professor of Public Policy, Departments of Society, Human Development and Health and of Epidemiology, Harvard School of Public Health (HSPH)

Speakers:

Elias Zerhouni, M.D., Director, U.S. National Institutes of Health

John Frank, M.D., Scientific Director, Institute of Population and Public Health, Canada

Mirta Roses Periago, M.D., Director, Pan American Health Organization

K. Sujatha Rao, I.A.S., Member Secretary of the National Commission on Macroeconomics and Health, India

Discussant:

Harvey V. Fineberg, M.D., Ph.D., President, Institute of Medicine

Q & A Panel:

Howard Koh, M.D., Professor of the Practice of Public Health, Associate Dean for Public Health Practice, HSPH, Facilitator

Judyann Bigby, M.D., Director of Community Health Programs and HMS Center of Excellence in Women’s Health, Brigham and Women’s Hospital

Christopher J.L. Murray, M.D., D.Phil., Professor of Population Policy, HSPH, Director, Harvard Initiative for Global Health

Atul Gawande, M.D., Assistant Professor of Surgery, Brigham and Women’s Hospital

Maria Glymour, S.D., Research Associate, Department of Society, Human Development and Health, HSPH

Making Disparities Count: From Government Statistics Systems to Action

Madeline Drexler

Introduction:

No data, no problem. Without sound population statistics, governments cannot truly fathom – or act on – the timeless problem of social inequalities in health. Yet data defining the groups at risk of health inequities are a two-edged sword, given past and present discrimination based on social categories at the heart of health disparities: socioeconomic position, race/ethnicity, nationality, gender, and sexual orientation.

Some health statistics systems collect socioeconomic information, but little on race or ethnicity; other systems collect complex and often inconsistent data on race and ethnicity, but little on socioeconomic position. Public health data collection cannot be divorced from national strategies on health disparities. At the same time, the wide-ranging ways in which various countries approach data collection are a window into culture, politics, and history.

Health disparities will never disappear without compelling proof that they exist in the first place. But what constitutes such evidence? How do a society's values and norms determine which personal data are worthy of collecting? And how are information systems being transformed in order to better portray the social patterning of health and disease?

On May 5, 2005, the last of three international symposia organized by the Working Group on Health Disparities at the Harvard School of Public Health examined how official statistics can shed light on modern health inequities. Participants included public health researchers and statisticians from the United Kingdom, France, Brazil, Zimbabwe, and the United States.

That the structure of society profoundly influences our bodies and minds is a long-standing truth – but one that needs constant reiteration in order to persuade governments to respond. “Without credible scientific evidence, everything else is opinion,” said Barry R. Bloom, Ph.D., Dean of the Harvard School of Public Health. Sound data can uncover the roots of disease, disability, and premature death; galvanize action; and show what does and does not work to eliminate unjust suffering. Routine monitoring of health inequalities keeps governments accountable to their citizens.

“For health disparities to count – that is, to matter – they must be counted,” said Nancy Krieger, Ph.D., Professor of Society, Human Development and Health at HSPH. She cited Edgar Sydenstricker, a twentieth-century public health pioneer in the United States, who said that the purpose of detailed surveillance was to “give glimpses of what the sanitarian has long wanted to see – a picture of the public-health situation as a whole, drawn in proper perspective and painted in true colors.”

Numbers and Values

Yet painting health disparities in true colors is a fraught enterprise. “The devil is in the details,” said Vickie M. Mays, Ph.D., M.S.P.H., Director of the UCLA Center for Research, Education, Training, and Strategic Communication on Minority Health Disparities. Which health indicators are most important? Which social groups deserve heightened attention? How should researchers define these target groups? What’s the best way to measure health disparities, or progress against them? How useful are qualitative data, such as health perceptions, attitudes, and beliefs? How can data best be leveraged for advocacy?

The answers to these questions hinge not only on science, but on values. Values “are at the heart of the debate,” said Godfrey Woelk, Ph.D., Chair and Associate Professor in the Department of Community Medicine at the University of Zimbabwe.

Indeed, throughout the symposium, it was impossible to separate the



Godfrey Woelk, Ph.D.

technical questions from their moral and ethical repercussions. “Data on health disparities do not fall fully formed out of the sky to land in our tally sheets in neat rows and columns, or enter our computers as discrete, multitudinous bits of information,” said Krieger. “Rather, the data of public health – those which are collected and analyzed from the stuff of the societies around us – are what those who make the data systems deem worthy of knowing. Whether and how health disparities are documented is thus

a key sign of the priorities of those in power.”

According to Krieger, these data are a two-edged sword. On one side “are past and present discrimination against individuals and groups, based on the ascribed social categories that lie at the heart of health disparities. These include socioeconomic position, race, ethnicity, nationality, gender, and sexuality.”

The flip side of the problem, she said, could be construed as, “‘No data, no problem.’ By this I mean the time-honored – or rather, I should say, time-disgraced – practice of sweeping problems under the proverbial rug by ensuring that no data exist to document them. Governments from antiquity to the present have engaged in this practice, whereby data that suggest unfairness in the body politic are conveniently hidden from view, and thus not permitted to be a public problem – even as the public endures the problem.”

The challenges of collecting health data range from the practical to the theoretical. One of the most vexing tasks turns out to be one of the most basic: how to define “race.” Though countries such as the United States rely on self-reported racial categories in census surveys, race is both a fluid and freighted concept, with different meanings in different contexts. “Race is not a biological construct, but rather one that is socially constructed,” said UCLA’s Mays, who recently completed a term as Chair of the Subcommittee on Populations of the National Committee on Vital and Health Statistics.

In the U.S., vital records on the same individual may contain contradictory information about race. “This is a country,” noted Mays, “in which you can

be born a minority and die white.” Part of the problem is that, depending on the situation, race can be self-reported, or it can be a judgment call made by others. As Mays put it, “Who I am depends on who you are.” And despite official guidance from the federal Office of Management and Budget, she said, people are often confused about the distinction between ethnicity, race, and nationality. For example, “Hispanic” or “Latino” refers to people of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin – regardless of skin color or facial structure.

The problem of defining race is not limited to the U.S. In Brazil, where race is self-reported in government surveys, there are, incongruously, more black men than black women. “It seems that there is still a tendency not to declare black or brown skin color,” explained Eduardo Mota, M.D., M.P.H., Associate Professor at the Institute of Collective Health of the Federal University of Bahia. Likewise, Brazil’s official mixed category of “brown” varies according to context; in the southern part of the country, it usually means people of partial African descent, while in northern and northeast Brazil it refers to the indigenous population. Other demographic categories embrace extraordinary diversity. “This is how we get ourselves in trouble here in the States,” said Mays. Within the American Indian category, for instance, are 562 federal recognized tribes. These tribes, along with those not

officially recognized by the government, spread out over 32 states and speak as many as 150 different languages.

“How meaningful is it to their health concerns when we group them all together under the rubric: ‘American Indians in the United States?’” Mays asked. Her answer: “In the process of classification of groups of



Eduardo Mota, M.D., M.P.H. and Vickie M. Mays, Ph.D., M.S.P.H.

people by race and ethnicity, it’s only useful and meaningful if it results in a better understanding of the factors or conditions that lead to health disparities.”

What will foster this deeper understanding? According to Mays: “We will reach this more meaningful analysis when we are able to ask not only about

race and ethnicity, but also about socioeconomic position, gender, age, and place – that is, where you live. Currently, few U.S. federal surveys ask all of these questions in the same survey. If the surveys do ask these questions, researchers are unable to access the data because of privacy and confidentiality concerns, or because of lack of accessible and secure data centers.”

Even within the same individual, racial self-identity may depend on the context. “In a health care setting, I may choose to share with you my American Indian heritage from my great-grandparents, because of some risk or protective factor that this may incur,” said Mays. But in other circumstances – say, if her answer was being tallied in order to justify starting a health program in her community – “I would mark black or African American.”

When racial categories overlap with economic groupings, interpretation becomes even trickier. The northern part of Brazil, said Mota, not only has higher concentrations of black and brown individuals, but also a higher concentration of people below the poverty line. Which variable, then, is more telling: race or socioeconomic position?

Race and ethnicity – the cornerstones of disparities research in the U.S. – may actually be markers for the social and psychological experiences of race and ethnicity. “Social deprivation may get us further along in this discussion,” said Woelk. “However, developing complex indicators of this kind brings an additional level of conceptual and practical complexity.”

Depicting health disparities raises other theoretical quandaries as well. For example, to what goals should a government aspire? Should its top priority be to improve the health conditions of the poorest? In the U.K., for example, the 2001 National Health Inequalities Targets are defined thus: “by 2010 to reduce by at least 10% the gap between the areas with the worst health and deprivation indicators (the ‘Spearhead’ group) and the population as a whole.”

Or should health officials take into account the full social gradient of health and disease, targeting those in the middle as well? “Simply comparing the extremes in terms of socioeconomic status – the richest quintile versus the poorest quintile – may be insufficient, as this may hide considerable variation in the middle groups,” explained Woelk. “For example, in the

current political and economic crisis in Zimbabwe, it is likely that the wealthiest group has become even wealthier, while the middle and poor have become significantly more disadvantaged.”

And how does one measure social deprivation? Again, it depends on the situation. “In a resource-poor setting, a huge part of the population may be socially deprived in absolute terms,” noted Woelk. “How then does one assess who is in most need, given the limited level of resources and the rudimentary nature of the health information system? In resource-rich countries, there is a different problem: that of measuring determinants against the context of relative plenty. Social deprivation may be relative to other groups.”

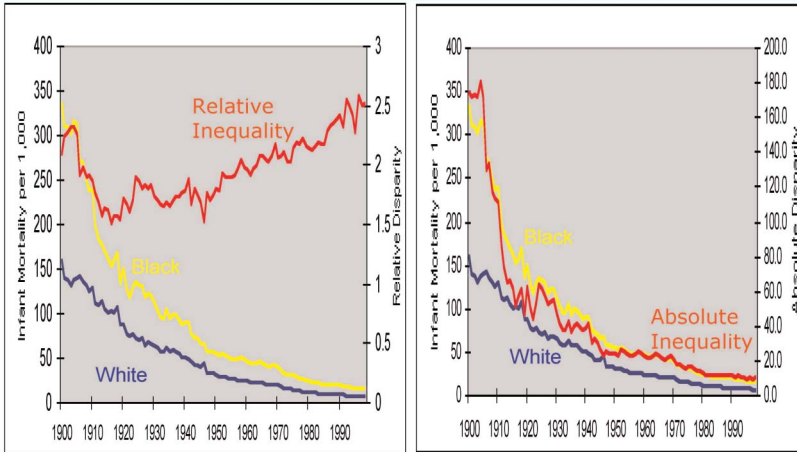
In other words, when measuring health disparities, who should comprise the reference group? Should researchers focus on relative or absolute measures of inequality – or both? Different answers to these questions imply different theories, different values – and different interventions, which can make a dramatic difference in an individual’s life. For example, when looking at infant mortality in the U.S. over the twentieth century, rates of absolute inequality have shrunk, as death rates among white babies have slowly declined and those among black infants have sharply dropped. But over the same time frame, relative inequality in infant mortality is wider than ever – underscoring the fact that governments must respond to both relative and absolute measures, and invest in health policies embracing the long-term perspective of preventing disease.

What data “count” in different countries?

Health disparities persist between and within nations – but how researchers frame these inconsistencies often reflects local mind-sets and constraints. In Brazil’s health information systems, data about education and occupation are only reported for births and deaths. “There are few studies of racial inequalities in health in Brazil. There are even fewer studies of socioeconomic inequalities,” said Eduardo Mota.

In the United States, race and education data form the pillars of health and vital statistics surveys. They are used as risk indicators for disease; to improve delivery of health services; and as markers of biological differences. The United Kingdom, by contrast, focuses on social class and occupation as key variables – class defined by mapping occupation and employment status onto a template of work-related class categories, from “professional” to “unskilled.”

Black – White Inequality in Infant Mortality over the 20th Century, USA



Lynch, 2004

Between 1900 and 1990, infant mortality rates declined dramatically for both the U.S. black and white population. But metrics of health disparities can vary according to method of comparison. Graph on left illustrates that while infant mortality rates fell steeply among both the black and white population, black/white relative risks increased. Graph on right shows that black/white absolute differences in rates decreased during same time period. This discrepancy occurs because relative risk picks up larger relative ratio differences among low rates, for which the absolute difference is small. To understand the magnitude of health disparities, data are needed on both relative and absolute differences.

Is one representation more revealing than the other? More useful? “What can the British system teach the American system, and vice versa, about the strengths and weaknesses of the variables we currently measure?” asked Mary Waters, Ph.D., Professor of Sociology at Harvard University.

Replying to Dr. Waters’ question, John Fox, Ph.D., Director of Customer and Stakeholder Engagement in the Health and Social Care Information Center, part of the U.K.’s new Special Health Authority, and a former director of health statistics in the Department of Health, noted: “When it comes to action, all dimensions of socioeconomic inequity and inequalities in health are important. First, they demonstrate that differences exist: in scale, direction, and patterns over time. They also provide an understanding of causal relationships, and suggest points and processes for intervention.” Fox went on to suggest that such philosophical differences in data-gathering



John Fox, Ph.D.

are forged by history (including a history of colonialism and its modern residue), cultural values, and by the sway of various research disciplines. These contrasts play out vividly in comparing health disparities data-gathering in the U.K. and France.

In the U.K., health statistics initially reflected mortality data in relation to age, gender, cause of death, and occupation, including detailed occupational codes. William Farr, the

visionary nineteenth-century health statistician, emphasized occupational groups as a way to gain insight into work-related hazards. By the early twentieth century, T.H.C. Stevenson introduced the Registrar General's Social Classes, which moved from detailed occupational categories to a schema of social standing – thus underscoring the role of social inequality in health.

With the introduction of the welfare state in England after World War II, many people assumed that social inequality in health had been solved. Adding to this sentiment was an artifact in the 1950 census, which erroneously reported that the highest mortality rates occurred in Social Class I – the captains of industry. This error further diffused interest in the subject.

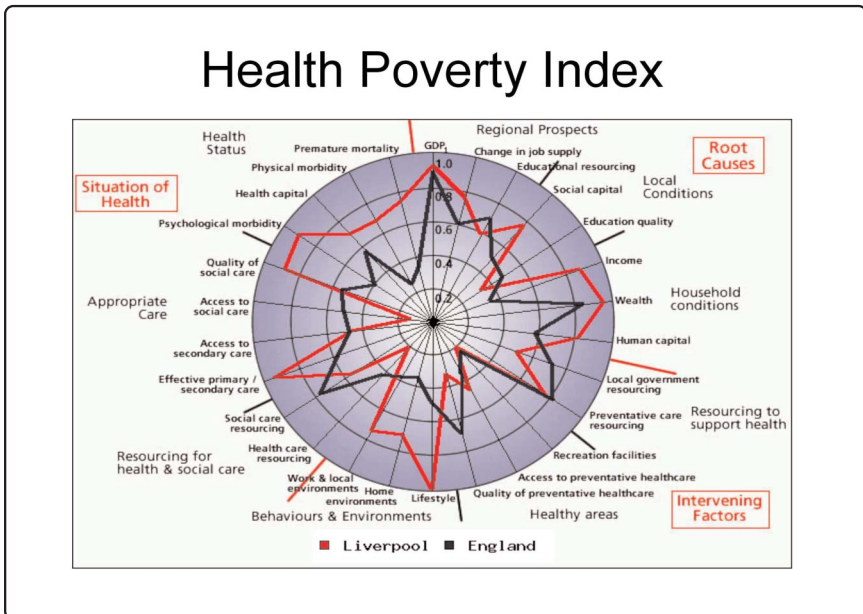
“In the 1960s, however, poverty was rediscovered,” Fox explained. With the public's conscience stirred, analysis of mortality data around the 1971 census once again highlighted social class differences based on occupations – and provided the empirical underpinnings of the watershed Black Report. Though published under the Conservative government of Margaret Thatcher in 1980 and ignored for 18 years until a Labor administration took power, the report placed “Inequalities in Health” (its title) firmly on the agenda in the U.K. and worldwide.

In 1991 – prodded by minority groups who sought the community benefits that flow from official recognition – the U.K. census added questions about ethnicity for the first time. In 2001, more detailed questions about ethnic group classifications were added, along with questions about religious affiliation.

As a result of these additions and refinements, the Labor government has

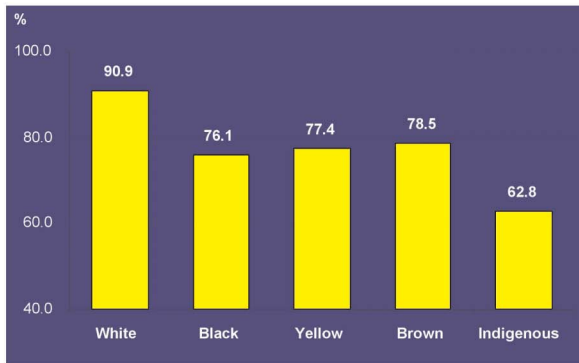
had at its disposal far more data than did earlier administrations on which to base its program aimed at reducing health disparities. “About one major report is issued per year,” noted Fox, “and a major theme concerns the monitoring of relevant indicators to see if progress is being made or not in reducing health inequalities.” One innovation is the government’s Health Poverty Index, which spans health status from the macro to the micro. In a single lively graphic, it depicts root causes, such as the job market and educational quality; intervening factors, such as recreation facilities and access to preventive healthcare; behaviors and environments, such as lifestyle and exposures; and health status, such as psychological illness and premature mortality. These charts, available on the web, compare the health of select cities to that of the population as a whole. The government’s key target groups are defined by socioeconomic status, ethnicity, gender, age, and locale.

Fox was asked to describe the rationale for the U.K.’s data-gathering priorities. “We were conscious that the U.S. gave prominence to race and education (years of), and that European countries used occupation and



The U.K. health poverty index shows the ratio of values for a given region of England (in this case, the city of Liverpool) compared to England as a whole. Using data from 2001, graph shows that Liverpool (red line) compared favorably overall to England (black line) with regard to economic determinants (“root causes”) of health disparities. Even so, the city fared worse with regard to overall “health situation,” especially in measures of psychological morbidity, physical morbidity, and premature mortality.

Percentage of women* who had 4+ prenatal care visits, by race/skin color, Brazil, 2002



Source: Sinasc, Ministry of Health

* Women who gave birth to a live born infant

Access to prenatal care in Brazil (2002) varies by race/ethnicity, with greatest access evident among white women and least among indigenous women. Other women are classified as “black” (i.e., of African ancestry), “yellow” (i.e., of Asian ancestry), and “brown” (“pareto,” of mixed ancestry).

education,” he explained. “Our problem with both race and education was that, although they are vital in determining an individual’s life chances, they are fixed over time, and so don’t allow measurement of changes in social position. The U.K. has had a strong sociology interest in social mobility, built around occupational mobility.”

France’s perspective on measuring health disparities is notably different. According to François Héran, Ph.D., director of France’s national population research institute (Institut national d’études démographiques, INED), its guiding principles relate to social and economic vulnerability. “The dominant criteria used by researchers on inequalities in health,” he said, “are socioeconomic groups and indicators of precariousness” – the latter term meaning social, economic, and material disadvantages. Héran added that French researchers have recently placed a special emphasis on “trajectories of inability” – that is, the many ways in which lifelong experiences and exposures shape the nature and degree of physical and mental disability.

In France, the boundary between social and private life is considered sacred

– and at first glance may seem to have constrained data collection related to health matters. Government administrative files (such as those used in tax collection or Social Security) are prohibited from containing “sensitive data.” What exactly is meant by “sensitive”? According to Héran, any information that reveals, directly or indirectly, a person’s politics, trade union membership, religious affiliation, philosophy, race, ethnic origin, sexual orientation, or state of health. “This prohibition is guided by a general principle: universalism,” he said. “The objective is, paradoxically, to combat discrimination. The idea is that a personal characteristic, which may be a ground for one’s condition, cannot be registered without serious reasons. This requires a very high level of legal scrutiny.”

But statistical surveys – including those used to measure health status – are permitted far more flexibility in the questions they can pose. Researchers are allowed to ask “sensitive” questions, provided that these questions are relevant to the objective of the survey, and provided that the subjects give their written consent. For example, in a large 1999 family survey, respondents were asked about former citizenship, country of birth, parents’ country of birth, languages handed down by the parents – all of which indicate ethnic origins. Other surveys on social mobility, education, and migration also contain these questions. Yet, said Héran, authorities do not

consider that such inquiries “directly or even indirectly indicate race or ethnicity – because we don’t use those terms.”



François Héran, Ph.D.

He conceded that the information these questions elicit is tantamount to what other nations’ surveys view as data about ethnicity. At the same time, he said, France’s quasi-ethnicity data are not used systematically as first-rank variables to interpret health disparities.

Anticipating the audience’s bewilderment, Héran rhetorically asked: “Why are French researchers so reluctant to use racial and ethnic variables?” His answers were a window into many traditional French beliefs – assumptions that are undergoing dramatic change as global forces impinge on the nation.

First, said Héran, many French citizens believe that France has not discriminated against its citizens in a way that demands present

compensation – a conviction he admitted was belied by France’s colonial legacy. Second, France does not have strong ethnic lobbying groups that insist on being recognized in government surveys and policies. Third, French government statisticians pride themselves on intellectual independence from other branches of government. “For example,” said Héran, “we don’t have the equivalent of a directive from the Office of Management and Budget, imposing an official classification on groups. It’s absolutely unthinkable in France that an official system would impose a classification, or impose a way of aggregating groups in case of multiple choices. French statisticians have the capacity of building categories – but they don’t want these categories being transformed into a legal instrument.” Finally, French statisticians harbor scientific “doubts,” he said, about the validity of self-declared ethnicity.

Yet, Héran adds, “Times are changing. We have more and more the feeling that discrimination is a very important issue that has been underestimated up until now.” One of the recent developments that has changed French officials’ minds is the massive influx of immigrants, including many who are HIV-infected. “Immigrants are strongly overrepresented among the population of HIV-infected persons,” Héran said, “especially women, and especially women from sub-Saharan Africa.” A French survey from 2003 revealed that foreign-born adults living with HIV made up 8.4 percent of the infected population; 1 out of 3 HIV-infected women was foreign-born; and 55 percent of HIV-infected immigrants had come from sub-Saharan Africa. Some researchers worried that release of those data would trigger a backlash. And according to Héran, “A few newspapers did exploit the data, in the sense of stigmatization.”

In France, then, how important is ethnicity in fathoming health equalities? Héran takes the middle ground: “Most researchers in health disparities in France think that categories in general – including ethnic categories – do matter. But these categories have less explanatory power than trajectories of precariousness” – that is, the interconnected and mutually reinforcing influences of poverty, joblessness, social deprivation, and unstable housing, all of which take their toll on health. Most immigrants, whether legal or illegal, he added, “are persons who happen to accumulate disadvantages.”

What isn’t counted (that should be)

While factors such as race and ethnicity, class and income, are the traditional signposts for health disparities, researchers are now looking at other, more subtle factors. One is ethnic identity – which, according to Vickie Mays,

“has to do with my experiences, my feelings of closeness to or distance from my particular racial or ethnic group, how much I embrace that culture, and the notion of social support and affiliation.” Which ethnic group a person subjectively holds close is often a clue to how that person accepts medical advice or health promotion messages – factors that contribute to health disparities. Ethnic identity is “an untapped but much needed area for further examination,” said Mays. “We may even find that racial and ethnic identification has greater stability than racial and ethnic classifications, particularly among individuals with mixed race ethnicities.”

In the U.S., other missing voices include small, clustered subpopulations, such as the Hmong in Minnesota; Mays wants to see ongoing surveys of these overlooked enclaves. Another oft-ignored group is incarcerated adults. “In any African-American or Latino community,” said Mays, “we have a fair number of young men in the 16 to 24-year-old range, whose health issues are not being captured.” When a prisoner returns to his community – sometimes either at risk for or infected with HIV or hepatitis – his beliefs and behaviors acquire great public health significance. “We want to know something about that young man.”

According to Godfrey Woelk, people who live outside the accustomed data categories, or who inhabit the intersections of known risk groups, may also be overlooked. “What about urban/rural disparities and differences – particularly in the U.S., where being rural means one is more likely to be poorer and more disadvantaged than being urban?” he asked. “What about the intersection of several groups who may be disadvantaged,” such as people who are both gay and black?

Developing nations pose special methodological problems, added Woelk. In these countries, information on basic socioeconomic status is often not available, because of a large peasant population and a sprawling network of informally employed workers. And while data are often available on the poorest groups in these countries – primarily because these groups make more use of government services – information is sometimes scanty on the most advantaged citizens, who rely on private facilities. “This makes comparisons between these groups more difficult,” said Woelk.

Bottom-up, not top-down

In the U.K., the health goals and policies that until recently were set by the national government are now being constructed bottom-up, based on the needs of local, patient-based systems. Significant sums of money are being

channeled to improve neighborhood statistics and to give people access to these numbers, in order to inform local health policies.

The bottom-up trend is not confined to Britain. Brazil is evolving from a centralized, federal health system to a decentralized, locally-managed operation, where community participation is key. “Citizen action and democratization,” said Mota, “may change not only how the people declare themselves in terms of race and health needs, but also how they use health information to make government act in terms of reducing health disparities.”

At the U.S. Department of Veterans Affairs, doctors are designing their own best practices and evaluating whether they are meeting targets that they themselves set. Elsewhere in the U.S., states are paving the way in gathering fine-grained health information for local use. Massachusetts, for example, has been a leader in collecting details on race, ethnicity, and national origin. The state allows mother and fathers to choose from 39 ethnic and national categories for self-identification on their newborns’ birth certificates. Drawing on this rich data lode, researchers have discovered that variation in birth weight within a black or Latino population is as great, if not greater, than between Latinos and other groups. They also found that among Chinese and southeast Asian immigrants, a mother’s birthplace is highly correlated to low birth weight in her offspring.

What will count in the future

If the symposium speakers’ dreams and predictions come true, the data that will illuminate tomorrow’s health disparities will be more abundant, finer-grained, up from the ground and, ideally, more likely to spur action. It will look at gender, age, relationship status, socioeconomic position, racial identity, acculturation, language use, and health conditions; it will fix its gaze across the whole lifespan, in utero to death; it will encompass international migration, neighborhood settings, and environmental hazards.

Information technology will further reshape the health disparities landscape. Because it is becoming easier to link separate government databases – social welfare statistics, for example, with hospital discharge information or birth certificate data – health officials may better understand why certain groups fare better or worse.

This technology will gain importance as governments install national health cards and other electronic pools of data. The United States is working on an

electronic health record, using unique personal identifiers as a means of reducing medical errors, boosting the quality of care, and tracking disparities. In Britain, billions of pounds are being allocated to establish similar electronic records so that general practitioners can enter patient information, which is then dispatched to multi-source data sets. Everywhere that such linkages occur, however, officials will have to grapple with issues of patient confidentiality and citizens' privacy.

In 2000, Brazil's public health services launched a pilot project for a national health card, covering 13 million people in 44 counties. The card registers data on age, sex, race (skin color)/ethnic group, place of birth, place of residence, education, and occupation. The goal is to integrate all health information systems – not only to capture outpatient data, but also to delineate local health conditions. A Brazil county map, for example, shows that where women have better access to health services, the infant mortality rate is lower.

At first, Mota admitted, some citizens were skeptical about the card. “They thought, ‘What kind of advantages will I have? Will I be assisted promptly? Will I have better health care because I use the card?’” But, he said, “What the government is trying to do is show that for those who use public health services, the card brings a lot of advantages We hope that it will give the people a sense of belonging to something, participating in a system, having rights, being part of the health system.”

Delivering on those promises, however, will be key to the card's success. “When we're dealing with very poor people, what can we offer to them besides this card? It's now on our minds,” he said. “Implementation has to be followed by the organization of health services, increasing the offerings of services, and better quality health services. It's not the card that will make things happen.”

Wherever health disparities exist, that is the goal: wielding data to make things happen. “Fundamentally, we believe that if we can measure it, lives will be changed,” said Robert Blendon, Sc.D., Professor of Health Policy and Political Analysis at the Harvard School of Public Health and Harvard's Kennedy School of Government. And yet, said Blendon, though statisticians have been tracking health disparities for centuries, disparities persist. “In our country, in 1900, the Surgeon General's report noted racial gaps in life expectancy and infant mortality of two-fold. The report then said, ‘This will be tough to deal with’ – and went on to the next page. So the question is:



(seated, left to right): Howard Koh, M.D., M.P.H., and Godfrey Woelk, Ph.D.; (standing): Robert Blendon, Sc.D.

What data could we collect, in what form, under whose auspices, that might change that outcome?"

The answer is unclear. "Ultimately, we need to use these data for policy and advocacy," said Woelk. "These data do not exist just for themselves and in themselves – they exist to be used for a purpose. Yet

there is a tension between the type of data most suited for advocacy and policy and that most suited for explanation. And we need to find a way of managing this tension in the most optimal way." As an example, Woelk cited the racial gap in mortality and morbidity in the U.S. "These data can be most readily and easily used in advocacy," he explained. "Yet, to understand why there are still these differences may entail more data and more variables" – such as nuanced analyses of social class and educational attainment. "In addition, as race is so controversial – so emotionally loaded – in the U.S., trying to shift the debate and engage more resources would probably be met with enormous resistance. Hence there would be a tension between trying to more effectively get to the heart of explaining these differences, while continuing to use the data for advocacy and policy."

In the future, government data may reflect more subtle sources and gradations of health risk. The U.K. is planning longitudinal studies that will track determinants of health over the life course. France is planning a 2007 survey that will feature what respondents consider to be their most salient experiences of suffering and discrimination. Another French survey – with the dual titles "Construction of Identities" and "Life History" – portrays its respondents in the round, asking about family life, hobbies, and other elements of self-image; immigrants will be purposely overrepresented in the sample. "This questionnaire includes a strand on perceived discriminations and feelings about mockery and insults," said Héran, "from things that are very psychological to things that are very objective and concrete. We tried to embrace a large scope of discrimination."

Ideally, such novel approaches will flesh out the root causes of health inequities. “Clearly,” said Godfrey Woelk, “the movement is toward a greater complexity.” Though digits and pixels may replace the artist’s pencils and palette, Edgar Sydenstricker’s vision of “the public-health situation as a whole, drawn in proper perspective, and painted in true colors,” may finally come true.

Symposium participants:

Moderator:

Nancy Krieger, Ph.D., Professor of Society, Human Development and Health, Harvard School of Public Health (HSPH)

Speakers:

John Fox, Ph.D.*, Director of Customer and Stakeholder Engagement, Health and Social Care Information Center, Special Health Authority, United Kingdom

François Héran, Ph.D., Director, Institut national d’études démographiques, Paris, France

Vickie Mays, Ph.D., M.S.P.H., Professor of Clinical Psychology, University of California-Los Angeles and Director, UCLA Center on Research, Education, Training, and Strategic Communications on Minority Health Disparities

Eduardo Mota, M.D., M.P.H., Chief of Health Statistics, Instituto de Saude Coletiva, Brazil

Discussant:

Godfrey Woelk, Ph.D., Associate Professor, Department of Community Medicine, College of Health Sciences, University of Zimbabwe

Q & A Panel:

Robert Blendon, Sc.D., Professor of Health Policy and Management, HSPH, Facilitator

Howard Koh, M.D., Professor of the Practice of Public Health, Associate Dean for Public Health Practice, HSPH, Facilitator

Mary Waters, Ph.D., Professor of Sociology, Harvard University

Evelynn Hammonds, Ph.D., S.M., Professor of the History of Science and African and African American Studies, Harvard University

David Rehkopf, M.P.H., doctoral candidate, Department of Society, Human Development and Health, HSPH

* *Dr. Fox was unable to attend the symposium. His presentation was made by Dr. Krieger. He did participate in answering questions for the preparation of this book.*

Themes for Action

Health Disparities & the Body Politic fostered frank cross-cultural discussions about the social determinants of health and governments' responsibility to address health inequalities. Among the series' key themes for action:

Overarching Themes:

- 1) Governments can – and should – address health disparities.
- 2) To address health disparities, governments need to:
 - a) fund researchers to focus on and refine the scientific theory behind social determinants of health,
 - b) fund practical interventions against health disparities.
 - c) encourage initiatives in all sectors of government to improve population health and reduce health disparities.
- 3) At the same time, even in the absence of perfect scientific evidence, governments must act to reduce health inequities and be held accountable for doing so.

Policy Themes:

- 1) Strategies to eliminate health disparities must emanate not only from the public health and medical care sectors, but from every government office where policies affect population health. These include offices in charge of labor, housing, urban planning, transportation, education, and environmental conservation.
- 2) To resolve health disparities, governments must bridge the traditional divisions between these different government sectors and departments. Government officials involved in intersectoral programs must share political responsibility for both successes and failures in addressing health inequalities.
- 3) The entire populace – but especially communities bearing the brunt of health inequities – must be engaged in current discussions about causes of, and solutions to, social disparities in health.

Research Themes:

- 1) Governments should expand funding specifically dedicated to health disparities research, with incentives to attract more researchers to the field.
- 2) National health research agendas must focus on social determinants of population health and interventions to address them, promoting research that cuts across myriad discrete diseases.
- 3) The structure and funding mechanisms of existing national research agencies, which typically focus on specific diseases and clinical treatments, must be reconfigured to address the causes of, and interventions for, health disparities.

Data Themes:

- 1) Governments and health systems must enhance data collection to better reveal and monitor health disparities and to produce policy-relevant statistics. Population data must be used to rectify – not perpetuate – health disparities and social exclusion.
- 2) Government reports on health status and health care should be routinely stratified according to race and ethnicity, socioeconomic position, gender, and other relevant categories of disadvantage and discrimination.
- 3) Government progress or setbacks in reducing health disparities should be continually monitored and annually reported.



Health Disparities & the Body Politic

A Series of International Symposia

What we today term “health disparities” – the consistent gap in physical and mental well-being between the most privileged members of society and the most socially and economically disadvantaged – launched the modern public health movement in the nineteenth century. Yet only in the past two decades have governments begun to focus explicitly on the deep-rooted social determinants of health and disease.

What are governments’ responsibilities to reduce these disparities? Should they enact policies extending beyond health agencies to encompass economics, housing, transportation, education, and other sectors? How should national research agendas spotlight the causes of, and solutions to, stark differences in health within a country’s population? What data should governments collect to more fully reveal health inequalities? How can these data be used to galvanize action?

In the spring of 2005, the Working Group on Health Disparities at the Harvard School of Public Health held three international symposia addressing these timely issues. Featuring senior governmental public health leaders and academic researchers from Latin America, Asia, Africa, Western and Northern Europe, as well as Canada and the US, the symposia explored both the successes and limitations of current policy approaches. By fostering frank cross-cultural discussion, the series also sought to inspire action on one of today’s most urgent public health problems. As Barry R. Bloom, Ph.D., Dean of the Harvard School of Public Health, summed it up, health disparities “perturb the consciences of people within the country and around the world.”

About the author: Madeline Drexler is a Boston-based journalist specializing in public health and medicine, and author of *Secret Agents: The Menace of Emerging Infections* (Penguin, 2003). She publishes widely in national magazines and newspapers. Drexler has a visiting appointment at the Harvard School of Public Health.

This book is also available for free on the web:
www.hsph.harvard.edu/disparities/book