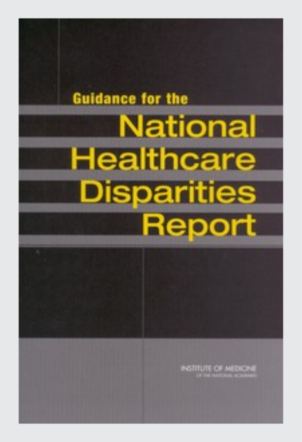

Guidance for the National Healthcare Disparities Report (2002)

DETAILS

215 pages | 6 x 9 | PAPERBACK
ISBN 978-0-309-08519-9 | DOI 10.17226/10512

CONTRIBUTORS

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SUGGESTED CITATION

Institute of Medicine. 2002. *Guidance for the National Healthcare Disparities Report*. Washington, DC: The National Academies Press. https://doi.org/10.17226/10512.

Guidance for the National Healthcare Disparities Report

Elaine K.Swift, *Editor*

Committee on Guidance for Designing A National Healthcare Disparities Report

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS
Washington, D.C.
www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 FIFTH STREET, N.W. Washington, DC 20001

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Support for this project was provided by Agency for Healthcare Research and Quality. The views presented in this report are those of the Institute of Medicine Committee on Guidance for Designing a National Healthcare Disparities Report, and are not necessarily those of the funding agencies.

International Standard Book Number 0-309-08519-5

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The report was reviewed by individuals chosen for their diverse perspectives and technical expertise in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments to assist the authors and the Institute of Medicine in making the published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. The committee wishes to thank the following individuals for their reviews of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the guidance offered by the committee nor did they see the final draft of the report before its release. Responsibility of the final content of this report rests entirely with the authoring committee and institution.

The review of this report was overseen by **Shoshanna Sofaer,** Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs, Baruch College, who was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered.

ACKNOWLEDGMENTS

Many individuals and organizations contributed to the work of the committee. The Agency for Healthcare Research and Quality (AHRQ) provided financial support and technical assistance. In particular, we would like to thank Carolyn Clancy, Acting Director, AHRQ; Helen Burstin, Director, Center for Primary Care Research; and Thomas W. Reilly, former director, National Quality Report.

We would also like to thank the authors of commissioned papers: Marian E.Gornick, Thomas A.LaVeist, Nicole Lurie, and Thomas C. Ricketts, III.

We acknowledge the experts who provided helpful background at the committee's organizational meeting held in January, 2002. They include Claudette Bennett, Chief, Racial Statistics Branch, U.S. Census Bureau; Adrienne Stith Butler, Program Officer, the Institute of Medicine's Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care; Diane Makuc, Director, Division of Health and Utilization Analysis, National Center for Health Statistics; Brian D.Smedley, Senior Program Officer and Study Director, the Institute of Medicine's Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care; Shelly Ver Ploeg, Senior Program Officer and Study Director, the National Research Council's Panel on DHHS Collection of Race and Ethnicity Data; and Helen W.Wu, Minority Health Project Director, National Quality Forum.

Many people contributed to the committee's workshop on the National Healthcare Disparities Report (NHDR) held in March, 2002. They include: Dennis P.Andrulis, Research Professor, State University of New York Health Sciences Center; Roger J.Bulger, President and Chief Executive Officer, Association of Academic Health Centers; J. Emilio Carrillo, Chief Executive Officer, New York Presbyterian Community Health Plan; Kathryn Coltin, Director, External Quality and Data Initiatives, Harvard Pilgrim Health Care; Merle Cunningham, Medical Director, Sunset Park Family Health Center Network of the Lutheran Medical Center, Brooklyn, New York; Gem P.Daus, Legislative and Governmental Affairs Coordinator, Asian and Pacific Islander American Health Forum; Arthur Elster, Director, Medicine and Public Health, American Medical Association; Vanessa Northington Gamble, Health Policy and Medical Education Consultant; Julianna S.Gonen, Director, Center for Prevention and Health Services, Washington Business Group on Health; Gina Gregory-Burns, Module Chief, Centro de Salud, Kaiser Permanente of San Francisco; Andrew J.Imparato, President and Chief Executive Officer, American Association of People with Disabilities; Keith Mueller, Director, Nebraska Center for Rural Health Research, University of Nebraska; David Nerenz, Director, Institute for Health Care Studies, Michigan State University; Darlene Nipper, Director, Multicultural and International Outreach Center, National Alliance for the Mentally Ill; Rea Pañares, Manager, Center for Prevention and Health Services, Washington Business Group on Health; Lucille Norville Perez, President, National Medical Association; Jeanette South-Paul (representing the American Association of Family Physicians), Chair, Department of Family Medicine, University of Pittsburgh School of Medicine; Ulder J.Tillman (representing the Association of State and Territorial Health Officials), Director, Delaware Health and Social Services Division of Public Health; Adewale Troutman, Director of Public Health Services, Fulton County Health Department, Georgia (representing the National Association of City and County Health Officers); and Steven Wilhide, Executive Director, National Rural Health Association.

PREFACE

Health care disparities deserve our attention. This nation believes that health care should not differ by race, ethnicity, socioeconomic status, or geographic location. And yet, ample evidence indicates that disparities exist.

The existence of health care disparities is common knowledge to some. However, as indicated by the headlines on the release of the Institute of Medicine report, *Unequal Treatment* (IOM, 2002), it is news to many. This is where the National Healthcare Disparities Report (NHDR), to be issued by the Agency for Healthcare Research and Quality (AHRQ), could make a major difference. As a new annual report to Congress on racial, ethnic, socioeconomic, and geographic disparities, it has the potential to educate both policy makers and the larger public on the extent of health care disparities and to focus their attention on areas where action is most needed. In other words, the NHDR could help to set the agenda for a major health care issue that too few are either familiar with or know how to effectively address.

To help the NHDR fulfill its potential, AHRQ commissioned the IOM to provide guidance on technical aspects of the report, including the measurement of disparities in health care access, quality, and service utilization; the measurement of socioeconomic status and geographic disparities; and the use of subnational datasets to support disparity measurement.

The IOM named the Committee for Guidance in Designing a National Health Care Disparities Report to carry out this work. Committee members contributed their considerable expertise in community health; health care delivery systems; health care disparity measurement and prevention; health care access; service utilization; quality measurement; and health care datasets.

The committee engaged several consultants to provide further background on the areas it was charged with studying. Commissioned papers by Marian E.Gornick (on the measurement of socioeconomic status), Thomas A.LaVeist (on the measurement of disparities in service utilization and quality), Nicole Lurie (on the measurement of disparities in access), and Thomas C.Ricketts, III (on the measurement of geographic disparities), are included in this publication.

The committee met twice. In January 2002, it held a meeting to gather background information from experts from AHRQ, the U.S. Bureau of the Census, the National Center for Health Statistics (NCHS), the National Quality Forum (NQF), and the IOM. Experts from AHRQ briefed committee members on the agency's work on health care disparities and the conceptual framework that will be used by both the NHDR and another new and related annual report to Congress, the National Healthcare Quality Report (NHQR). Members were also briefed on Census 2000 findings on race and ethnicity as well as on a recent government report from NCHS on geographic health care disparities. Lastly, the committee learned about other studies on disparities by the NQF and the IOM. During this meeting, it also met in closed and open session to plan its work and to hold preliminary discussions on its charge.

In March 2002, it held another meeting to hear presentations from the consultants and testimony from invited academics, clinicians, advocates, and other experts in health care disparities. Drawn from across the country, these experts offered their perspectives on what the content of the report should be, including the areas of disparities that should be measured; the need for accurate data; and the different ways in which policy makers at the federal, state, and local levels might find the report useful. The committee also met in closed session to reach agreement on the response to its charge.

Following the March meeting, committee members continued to communicate by telephone and electronic mail. The guidance that the committee has issued is highlighted in the text of the Executive Summary and the Committee Report and is based on consensual agreement. This guidance addresses issues that include the challenges of adequately measuring racial and ethnic health care disparities; the need for an AHRQ-sponsored research initiative on the relationship between socioeconomic status and health care; and the primacy of disparities in health care access. The committee's guidance also focuses on the importance of including measures of high and low utilization of certain health care services, of presenting data on disparities at the state level and along the rural-urban continuum, and of standardizing core elements of subnational datasets. It also addresses AHRQ's need for adequate resources to carry out technical tasks for the report.

The committee looks forward to the publication of the first and subsequent editions of the NHDR. By attracting attention and raising awareness, it could help to set the standard for other health care reports. Even more importantly, by providing authoritative information on areas ripe for action, it could play a central role in speeding the elimination of health care disparities and making good the promise of genuine health care equity.

Sheldon Greenfield,
Chair

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EXECUTIVE SUMMARY

Disparities in health care are among this nation's most health care problems. Research has extensively document pervasiveness of racial and ethnic disparities. Minoritiy poorer quality care in such important areas as cardiovascul cancer, asthma, and diabetes (IOM, 2002b). Research extensively documented geographic disparities, with level care quality varying by region and state (Dartmouth Atlas Care Working Group, 1999; Jencks et al., 2000). Society disparities are also quite common: millions of low income lack insurance and receive poorer health care quality over 2002a).

As part of a national effort to eliminate health care Congress in 1999 required the Agency for Healthcare Research Quality (AHRQ) to produce a new annual report to be National Healthcare Disparities Report (NHDR). The first the NHDR will be published in fiscal year 2003 (October September 30, 2003). Beginning in fiscal year 2003, A produce another annual report mandated by Congress, the Healthcare Quality Report. Together, these reports will came to the "inequality of quality" (Fiscella et al., 2000, p. 257 can be defined as "the degree to which health services for and populations increase the likelihood of desired health outcomes are consistent with current professional knowledge" (IOM 21).

AHRQ commissioned the Institute of Medicine establish a committee to provide guidance on the NHDR is of access to health care, utilization of services, and the services received. The committee was asked to con population characteristics as race and ethnicity,[1] society

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[1] Race and ethnicity are defined using the categories in the Office Management and Budget (OMB) Directive 15: American Indian or

status,[2] and geographic location. It was also asked to examine factors that included possible data sources and types of measures for the report.

The Committee for Guidance in Designing a National Healthcare Disparities Report was created in 2001. It focused on five areas critical to the NHDR:

1. Measurement of socioeconomic status in disparities research;
2. Measurement of disparities in health care services and quality;
3. Measurement of disparities in health care access;
4. Measurement of geographic units in disparities research; and
5. Subnational datasets.

GUIDING THE NATIONAL HEALTHCARE DISPARITIES REPORT

While socioeconomic status is not the only factor related to racial and ethnic health care disparities, it is a highly important one because racial and ethnic minorities are more likely to have lower socioeconomic status. Using socioeconomic status as a stratifier in collecting data and as a control in analysis would more clearly indicate the extent to which disparities result from racial and ethnic factors rather than from socioeconomic status. It should be noted that adjusting for socioeconomic status almost always reduces, though seldom eliminates, the effects of race and ethnicity on the health care that a patient receives (IOM, 2002b).

1. The National Healthcare Disparities Report should present analyses of racial and ethnic

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Native; Asian; Black or African American; Native Hawaiian or other Pacific Islander; and White. OMB Directive 15 defines ethnicity separately from race, and it is limited to Hispanic or Latino or not Hispanic or Latino.

[2] Socioeconomic status is a complex concept that combines dimensions of social and economic resources as well as societal ranking or prestige.

disparities in health care in ways that take into account the effects of socioeconomic status.

There are questions about how best to measure the influence of socioeconomic status on health care. Socioeconomic status is mainly measured using income and education. However, both have different meanings for different racial, ethnic, and other populations, and their use can be problematic when this variation is not taken into account. Income, for example, more accurately captures the financial resources of minorities than Whites, who are more likely to have assets such as real estate and other investments (Oliver and Shapiro, 2001; Smith, 2001).[3] Educational levels for Whites and minorities can have different implications because minorities often attend schools with fewer resources and less prestige. Similarly, an immigrant's degree earned from a school abroad may be valued less than a degree earned at an American school.

AHRQ should sponsor research on the relationship between socioeconomic status and health care as a basis upon which to construct more accurate and meaningful measures. Areas where research is needed include identification of the dimensions of socioeconomic status that most influence health care access, service utilization, and quality, and the reasons for their influence. Research is also needed to evaluate how well measures of socioeconomic status are associated with access, use, and quality of health care services. In addition to income and education, these measures include but are not limited to total wealth, occupation, and deprivation indices, that is, composite measures formulated from such variables as employment status and access to a car.

2. AHRQ should pursue a research initiative to more accurately and meaningfully measure socioeconomic status as it relates to health care access, service utilization, and quality.

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[3] For example, in 1994, White households had a median income of $33,600; Black households, $20,508; and Hispanic households, $22,644. In terms of net financial assets, White households had a net worth of $7,400; Black households, $100; and Hispanic households, $300 (Oliver and Shapiro, 2001).

Access to health care is particularly important for racial and ethnic minorities. They have fewer economic resources and more frequently live in disadvantaged geographic areas. They are more likely to report that they are in fair or poor health and are more likely to receive discriminatory treatment in the health care system. In addition, they are less likely to get preventive services and attention for many chronic conditions. They also have higher mortality rates from a range of conditions (IOM, 2001a; IOM, 2002b).

Access applies to entry *within* the system of care as well as entry *to* the system of care. While access to the system of care may mean that a patient gets emergency or primary care, access within the system of care is necessary to obtain such vital services as specialized care, prescription drugs, and follow-up treatment. Access to and within the system of care is influenced by such diverse factors as insurance coverage, the availability of transportation, language translation services and other aspects of cultural competency, and time that can be taken from work.

3. Access is a central aspect of health care quality. As such, the National Healthcare Disparities Report should give it prominent attention.

In general, minorities receive fewer services than advantaged populations. However, in certain cases, minority populations receive more services, and they usually indicate poor prior care (LaVeist, 2002). For example, African Americans with diabetes are more likely to have limbs amputated than Whites. Including measures of both kinds of disparities in the NHDR would provide a fuller picture of the inferior health care quality often experienced by minorities (IOM, 1993).

4. The National Healthcare Disparities Report should include measures of high utilization of certain health care services that indicate poor health care quality. It should also include measures of low utilization of certain health care services, which are more commonly used to indicate poor health care quality.

While the NHDR should feature national level data, it should also include data by smaller geographic units that interest the report's primary audiences of members of Congress, other policy makers, and consumers. For example, analyses such as state-by-state comparisons on health care are familiar and meaningful to members of Congress, other policy makers, and consumers (IOM, 2001b). Many members of Congress also represent rural and urban areas, making them highly relevant (Ricketts, 2002).

5. The National Healthcare Disparities Report should present data on disparities at the state level. It should also present data on disparities along a rural-urban continuum.

National datasets such as the Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey (NHIS) currently do not have the sample sizes needed to supply data for the NHDR on geographic disparities by regions or states. Their sample sizes are also too small to supply data on disparities for such racial and ethnic subpopulations as Chinese, Korean, and Indian Asian Americans (Reilly, 2002).

Subnational data sources hold promise for supporting measures in the NHDR. Many racial and ethnic subpopulations are geographically concentrated and well represented in survey samples. However, they also have a number of limitations. For example, subnational datasets measure race and ethnicity in different ways. While some allow respondents to choose more than one racial category, others do not. In some, race and ethnicity are reported by respondents, while in others they are reported by observers. AHRQ should work with public and private organizations that sponsor key subnational data sources to address issues of standardization.

6. In the future, if AHRQ continues to rely on subnational data sources for the National Healthcare Disparities Report, it should work with public and private organizations that sponsor key subnational data sources to identify core elements in surveys that can be standardized.

AHRQ must use measures and datasets that meet rigorous scientific standards if it is to provide a credible and useful report for policy makers and other audiences. To do so, AHRQ will need expertise and substantial means to carry out such tasks as identifying appropriate ways to measure socioeconomic status in relation to health care disparities and formulating and evaluating measures of health care access, service utilization, and quality based on their validity, reliability, and other criteria. Measures require data to support them. However, the agency must have access to the expertise and resources needed to improve the usefulness of subnational datasets to the NHDR.

7. AHRQ should receive adequate resources to develop datasets and measures needed for the National Healthcare Disparities Report.

The NHDR could benefit from an association with the NHQR. In addition to the conceptual framework that the reports share, measurement selection for the NHDR could be guided by the process used for selecting measures for the NHQR. Both could feature the same measures where those in the NHQR have special relevance to areas where disparities are particularly large, are likely to result in death or serious illness, or are amenable to improvement. Measures included in the NHQR will be selected from a larger set of measures AHRQ will use to monitor health quality. The NHDR could also be drawn from measures in this larger set if they are more relevant to disparities. Lastly, the NHDR could make use of measures of disparities in health care access, utilization, and quality described in commissioned papers by LaVeist (LaVeist, 2002) and Lurie (Lurie, 2002).

CONCLUSION

The National Healthcare Disparities Report could play a major role in raising awareness of racial, ethnic, socioeconomic, and geographic health care disparities. It could also help to guide Congress and other policy makers in areas that require action to eliminate disparities.

The Committee's guidance on data and measurement development as well as report content would enhance the contributions that the NHDR could make to this critical area of health care. The Committee's guidelines are summarized in Table ES–1.

TABLE ES–1 Guidance for the National Healthcare Disparities Report

1. The National Healthcare Disparities Report should present analyses of racial and ethnic disparities in health care in ways that take into account the effects of socioeconomic status.
2. AHRQ should pursue a research initiative to more accurately and meaningfully measure socioeconomic status as it relates to health care access, service utilization, and quality.
3. Access is a central aspect of health care quality. As such, the National Healthcare Disparities Report should give it prominent attention.
4. The National Healthcare Disparities Report should include measures of high utilization of certain health care services that indicate poor health care quality. It should also include measures of low utilization of certain health care services, which are more commonly used to indicate poor health care quality.
5. The National Healthcare Disparities Report should present data on disparities at the state level. It should also present data on disparities along a rural-urban continuum.
6. In the future, if AHRQ continues to rely on subnational data sources for the National Healthcare Disparities Report, it should work with public and private organizations that sponsor key subnational data sources to identify core elements in these surveys that can be standardized.
7. AHRQ should receive adequate resources to develop datasets and measures needed for the National Healthcare Disparities Report.

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COMMITTEE REPORT

It is well established that race, ethnicity, socioeconomic status, and geographic location are among the factors that influence health care independent of patient need (IOM, 2002b; National Center for Health Statistics, 2001; National Quality Forum, 2002; Nerenz et al., 2002). Growing concern over racial, ethnic, geographic, and other disparities in health care prompted Congress in 1999 to require the Agency for Healthcare Research and Quality (AHRQ) to produce a new annual report beginning in fiscal year 2003 (October 1, 2002 to September 30, 2003). The National Healthcare Disparities Report (NHDR) will take its place alongside another new annual report to Congress to be called the National Healthcare Quality Report (NHQR). Together, they will provide policy makers, consumers, and others with a more complete picture of the health care that Americans receive and of the areas that need attention.

To help it address a number of technical issues related to the NHDR, AHRQ commissioned the Institute of Medicine (IOM) to examine issues related to racial, ethnic, geographic, and socioeconomic access to—and use of—health care services, as well as to the quality of care provided.[1] In addition, the IOM was asked to take into account explanatory factors such as spoken language, literacy, culture, community influences, and attitudes toward health. Also, the

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[1] As a federal agency AHRQ must use the racial categories specified by the federal Office of Management and Budget (OMB) in OMB Directive 15: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or other Pacific Islander; and White. OMB Directive 15 defines ethnicity separately from race, and it is limited to Hispanic or Latino or Not Hispanic or Latino. Currently, there is not a standardized treatment of racial and ethnic subpopulations. See National Quality Forum (2002) for a discussion of the lack of subpopulation definitions.

IOM was asked to examine measures and data sources that could be used in the report.[2]

AHRQ requested that the IOM consider issues related to the NHDR within the context of the framework developed by the IOM's Committee on the National Quality Report on Health Care Delivery in its study, *Envisioning the National Health Care Quality Report* (IOM, 2001c). The framework consists of a matrix of components of health care quality and consumer perspectives on health care needs. The four components of health care quality are based on those presented in *Crossing the Quality Chasm* (IOM, 2001b): safety, effectiveness, patient centeredness, and timeliness. There are four consumer perspectives on health care needs: staying healthy, getting better, living with illness or disability, and coping with the end of life.[3]

In the framework, equity is a component that applies to both populations and individuals. It is defined in terms of "providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status" (IOM, 2001b, p. 6). For populations, equity means reducing disparities in the use of health care services that are related to personal characteristics such as race, ethnicity, socioeconomic background, and geographic location. Research documents that insurance coverage is particularly important to achieving this goal (IOM, 2001a; IOM, 2001b). For individuals, it refers to the receipt of safe and effective services based on need. As Figure 1–1 shows, the framework treats equity as a cross-cutting factor, applicable to each cell of the matrix.

AHRQ will use the same framework for the NHDR. This reflects the agency's plan to make health care quality a major focus of this report, which is appropriate since disparities often represent an

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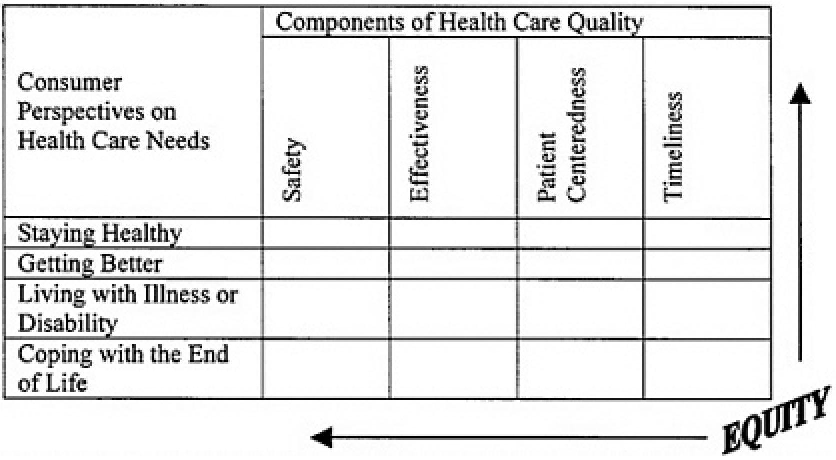
[2] At the same time that the IOM Committee for Guidance in Designing a National Health Care Disparities Report was meeting, the National Quality Forum (NQF) was producing a report (National Quality Forum, 2002) that addressed the issue of quality measures best suited to capturing health care disparities. To avoid duplicating the work of the NQF, the committee focused on matters relating to service utilization and access.

[3] See chapter 2 of IOM (2001c) for definitions of these terms and an elaboration on the framework as a whole.

"inequality in quality" (Fiscella et al., 2000, p. 2579). Within the framework, the NHDR will highlight health care issues related to equity and the extent to which health care disparities undermine its achievement.

FIGURE 1–1 Framework for the National Healthcare Quality Report and the National Healthcare Disparities Report



Consumer Perspectives on Health Care Needs	Components of Health Care Quality			
	Safety	Effectiveness	Patient Centeredness	Timeliness
Staying Healthy				
Getting Better				
Living with Illness or Disability				
Coping with the End of Life				

To carry out this work, the IOM established the Committee for Guidance in Designing a National Health Care Disparities Report. The committee met twice. At its initial meeting in January 2002, it planned its work and discussed its charge. It also was briefed on disparities-related issues by experts from AHRQ, the U.S. Bureau of the Census, the National Center for Health Statistics (NCHS), the NQF, and the IOM. The committee commissioned five consultants to address key research topics. At the March meeting, they delivered presentations on the following: Marian E.Gornick (independent consultant): measurement of socioeconomic status in disparities research; Thomas A.LaVeist (Johns Hopkins University): measurement of disparities in health care services and quality; Nicole Lurie (RAND): measurement of disparities in health care access; Thomas C.Ricketts, III (University of North Carolina-Chapel Hill): measurement of geographic units in disparities research; and Ross Arnett (independent consultant): subnational datasets for use in the NHDR. At the March meeting, the committee also heard testimony from a number of other invited experts on health care disparities. These experts participated in one of the following panels: Disparities in Public Health; Disparities in Health Care Purchasing and Providing; Disparities in Health Care Delivery; or General Comments on Disparities.[4]

1–1. MEASUREMENT OF SOCIOECONOMIC STATUS IN DISPARITIES RESEARCH

Socioeconomic status is a complex concept that combines dimensions of social and economic resources as well as societal ranking or prestige. As such, it is related to social stratification, or “a system of social relationships that determines who gets what, why” (Kerbo, 1996, p. 11); social class, or “social groups arising from interdependent economic relationships among people” (Krieger et al., 1997, pp. 344–5); and other concepts identified with social inequality. Socioeconomic status influences health care in a number of ways. For example, an individual’s or family’s material circumstances affect health care access, services, and quality since they are directly related to adequate insurance coverage (IOM, 2001a; Lurie, 2002). Social status affects health care by influencing the ways in which individuals are perceived. For example, health care professionals are more likely to take seriously those who appear to have higher status (Magnus and Mick, 2000). In addition, education, well-connected social networks, experience in dealing with professionals, poise, and other aspects of higher social position can help patients effectively navigate a complex health care environment that features health care insurers and individual and institutional providers, among others. The ability to navigate this system can in turn influence the access, services, and quality of care that patients receive (Gornick, 2002; IOM, 2002b; Magnus and Mick, 2000).

The NHDR should contain analyses of racial and ethnic health care disparities that reflect the influence of Socioeconomic status. There are two main reasons for paying particular attention to Socioeconomic status. First, it would help to clarify the extent to which health care disparities result from Socioeconomic factors or from racial

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[4] See Appendix I for the Workshop Agenda and Appendix II for a summary of the public testimony.

and ethnic factors. Socioeconomic status is associated with race and ethnicity: racial and ethnic minorities are more likely to have lower socioeconomic status as measured in a variety of ways, including income, wealth, and education (National Research Council, 2001). Better understanding the relative effects that socioeconomic factors and racial and ethnic factors have on disparities is critical to identifying ways to eliminate them. Secondly, socioeconomic status deserves attention in its own right because it has a pervasive influence on both health status and health care. It is linked to health status in a number of ways. For example, those with lower socioeconomic status are more likely to lead socially isolated lives and to be unemployed or to work at jobs that are unfulfilling and stressful (Marmot, 2002). They more frequently live in places where it is difficult to buy fresh food and to exercise. Their environments are more apt to be polluted by such elements as hazardous wastes, unclean air, and lead paint (IOM, 1999). Socioeconomic status is also linked to differences in health care. Those with lower socioeconomic status are more commonly uninsured and have more limited access to preventive, primary, and specialized care. They are more likely to suffer adverse health outcomes and poorer health status (IOM, 2001a; IOM, 2002a).

1. The National Healthcare Disparities Report should present analyses of racial and ethnic disparities in health care in ways that take into account the effects of socioeconomic status.

For the NHDR to adequately take into account the effects of socioeconomic status, it should use socioeconomic status in two different ways: first, as a stratification variable in collecting sample data on racial and ethnic disparities in health care access, service utilization, and quality; and secondly, as an independent variable that serves as a control in analysis. Stratification would ensure adequate sample sizes of racial and ethnic populations with varying levels of socioeconomic status. Further, controlling for socioeconomic status would help to identify the extent to which disparities result from factors associated with race and ethnicity and the extent to which they result from factors associated with socioeconomic status. Using socioeconomic status as both a stratifier and control would be more likely to yield reliable findings of the role that socioeconomic status plays in racial and ethnic health care disparities. Using socioeconomic status only as a control variable assumes that a single model fits all subgroups in the population. This assumption, however, may not be valid. It may be, for example, that there is a significant positive relationship between socioeconomic status and a particular dependent variable among Blacks, but no significant relationship among Whites. There might even be a significant negative relationship between the variables among Asian Americans or American Indians. The NHDR, therefore, should include analyses that stratify by race and ethnicity to explicitly test whether the relationships among variables are the same when each subgroup is considered in turn.

To understand the independent impact of socioeconomic status on disparities, it is important to identify which of its dimensions have greater effects on health care, facilitating the development of more targeted and effective interventions. For example, are material resources more strongly related to receipt of quality care than educational level or occupation? If material resources are critical, then efforts can be focused on formulating and implementing policies and interventions to enhance economic well-being or to reduce the cost of medical care. If occupation is strongly associated with receipt of quality care, interventions can be focused on those in affected jobs. It is also important to determine the extent to which disparities are rooted in racial, ethnic, or socioeconomic issues. For example, is poor access to specialized care more strongly related to race or to income? Clarifying the impact of socioeconomic status on disparities would enhance the accuracy of the NHDR as well as add to the mix of issues that interventions need to address.

The complexity of socioeconomic status is more exactly expressed in the many different ways that it has been operationalized (Liberates et al., 1988). There does not appear to be a single right way to operationalize it. Different measures either taken by themselves or together capture important aspects of socioeconomic status and how it affects health care (Gornick, 2002; Liberates et al., 1988). There are several major approaches to measuring socioeconomic status. They include income, wealth, education, poverty level, occupation, and deprivation indices, which are composite measures consisting of such variables as employment status and access to a car. Some of the major approaches, namely income and education, are commonly used in the research literature. Wealth, including property holdings and income from investments, is less often used. Occupation is more frequently applied in British studies of the relationship between socioeconomic status and health status. Deprivation indices have not been extensively used in studies of health care.

Each approach has advantages and disadvantages (Gornick, 2002). At present, education and income are the measures of socioeconomic status for which enough data are available for use in the NHDR. Education is a stable measure for adults, with nearly complete reporting in surveys. Income is included in most publicly reported datasets. Each has significant advantages, which have been noted by Gornick (Gornick, 2002) and others (Krieger et al., 1997). Survey respondents readily report information on their educational backgrounds, and education is commonly regarded as a meaningful and valid measure of socioeconomic status. Data on income are relatively accessible to researchers.

It should also be noted that each has important disadvantages. Education may have different social meanings across generations and races and ethnicities. For example, a high school degree for the postwar generation was associated with more economic opportunity than a high school degree for younger generations. In addition, minorities often attend schools with fewer resources and less prestige, which can make their educational achievements less valued. Similarly, an immigrant with a college degree from another country may not receive the same economic returns as a person who graduated from an American college. Income data are missing for a significant proportion of people in most health care surveys. Survey respondents also tend to underreport income. In addition, income more accurately captures the financial resources available to minorities than to Whites, who are more likely to own real estate and have other investments and assets (Oliver and Shapiro, 2001; Smith, 2001).

Is education or income the better measure of socioeconomic status? Education and income are related variables: higher educational levels are associated with higher income levels. But this does not mean that they are interchangeable. For example, Gornick (Gornick,

2002) examined the proportion of White and Black women over 65 who received mammograms, flu shots, and Pap smears in 1998 by two levels of income (below and above $25,000) and two levels of education (less than high school and high school or more). The data reveal disparities by race whether socioeconomic status is measured in terms of income or education. Nonetheless, stratification by income and education yielded appreciably different numbers for analysis. Almost nine times the number of Black women (985,000) had a lower level of education than the number (111,000) who had a lower level of income. More than two times the number of White women had a lower level of income (11,434,000) than education (5,472,000). As this also suggests, analyses of the relationship between socioeconomic status and health care can vary depending on the quality indicator used and the population or subpopulation examined.[5]

Which measure or measures of socioeconomic status should AHRQ use in the NHDR? This is an important question. To adequately answer it will require a clearer understanding of the relationship between socioeconomic status and health care. There is a striking dearth of studies of the relationship of socioeconomic status to health care. Income does appear to be a critical variable, and it is related to insurance coverage. Those on the higher end often receive private health insurance as a work-related benefit. While some on the lower end of the income distribution may qualify for Medicaid depending on federal and state eligibility requirements, they are most likely to lack it. Many of those in the middle also lack health insurance (IOM, 2001a).

However, research does not show whether income mainly accounts for the relationship of socioeconomic status to health care. Nor does it indicate whether other variables with which income is associated actually account for more of the relationship. For example, research reveals that those at different income levels tend to use the health care system in different ways. Those with higher incomes have a greater tendency to use preventive services while those with lower incomes have a greater tendency to use acute care services due in part

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[5] It should also be noted that analyses can vary depending on the cutpoints used for education, income, and other measures of socioeconomic status (Liberates et al., 1988).

to greater morbidity. This pattern holds true even when cost is not a factor, as is the case with the use of influenza vaccinations by Medicare beneficiaries, a benefit that is completely covered by Medicare (Gornick, 2000). Is it income per se that accounts for these different patterns? Or is it factors with which income is associated, such as access to transportation and proximity to health care providers?

2. AHRQ should pursue a research initiative to more accurately and meaningfully measure socioeconomic status as it relates to health care access, service utilization, and quality.

AHRQ should sponsor research on the relationship of socioeconomic status to health care. Exploration of the relationship between socioeconomic status, health care, and other factors such as race and ethnicity would help to identify the most appropriate measures of socioeconomic status to use in studies on health care disparities. Appropriate measures in turn would help to indicate which of the many dimensions of socioeconomic status are most likely to affect a particular aspect of health care and therefore to be associated with outcomes.

The following are examples of important areas where more research is needed:

- In general, which dimensions of socioeconomic status most affect health care and why? How strongly are different measures of socioeconomic status such as income, education, and occupational prestige associated with health care?
- Should socioeconomic status be studied at the individual, household, or community level? Research indicates that different races, ethnicities, and nativities call for different levels of analysis. For example, community-level measures may better capture the social and economic status and environments of immigrants and some races and ethnicities while individual- and household-level measures may be more appropriate for others (Krieger et al., 1997).

- The status dimension of socioeconomic status is particularly understudied, both in terms of how it does and does not empower patients and how it affects the relationship that patients have to providers and other aspects of the health care system. How might status be operationalized? Is income sufficient? Or are other measures of status, such as car and home ownership, needed?
- Is one measure of socioeconomic status adequate? Or do composite measures, such as deprivation indices, perform better?
- Are different dimensions of socioeconomic status implicated in preventive, acute, or other aspects of health care? For example, is it the case that attitudes toward health, health literacy, cost and availability of transportation, or work schedule flexibility influence a patient's use of preventive services, while income more strongly accounts for use of acute care?
- The NHDR will be focused on issues of access to and within the health care system, health care service utilization, and health care quality. How are patterns in each related to a patient's socioeconomic status? Are the results of quality measurement affected by the socioeconomic status of the population more likely to use particular services?

1–2. MEASUREMENT OF DISPARITIES IN ACCESS TO AND WITHIN THE HEALTH CARE SYSTEM

Access can be defined as entry *to* the system of care as well as entry *within* the system of care. Access is a central aspect of quality, and the NHDR should give it prominent attention. The framework of the NHQR treats access as an important aspect of all four components of health care quality: safety, effectiveness, patient centeredness, and timeliness. However, access deserves greater prominence in its own right because it is a critical starting point for quality care. As such, it is a fundamental aspect of quality, especially for racial and ethnic minorities, those with fewer socioeconomic resources, and those in disadvantaged geographic areas (IOM, 2001a; IOM, 2002a; IOM, 2002b; National Center for Health Statistics, 2001).

3. Access is a central aspect of health care quality. As such, the National Healthcare Disparities Report should give it prominent attention.

Access should be reconceptualized as a dimension of health care rather than as a dimension of medical care alone. Access to physicians and other medical care professionals is essential: it provides the diagnoses, medical interventions, and monitoring that can be critical to preventing and treating illness. However, primary care physicians typically coordinate care received from other health care specialists including nutritionists, dentists, and occupational, physical, and mental health therapists.

Disparities in access depend in part on the social and human capital of the patient and the community. Some factors play important roles, including adequate and secure material resources; community norms that favor healthy lifestyles; social support networks supplied by families, friends, and religious, professional, social, and civic organizations; the availability of safe and convenient places to exercise and shop for fresh food; well-developed transportation systems; high literacy rates; and low crime rates (Aday, 2001; Fiscella, 2002; IOM, 2002b; Lurie, 2002; Ricketts, 2002).

As such, a wide range of measures of access influence entry to the system of care as well as entry within the system of care. They include factors as diverse as the extent of insurance coverage, language access services, and other aspects of culturally competent care. For example, cultural competency is critical in the diagnosis and treatment of mental illness: behavior that is interpreted as mental illness in one culture may be an appropriate way of displaying emotion in another culture (DHHS, 1999).

The following are some of the new measures of access suggested by Lurie for development and use in the NHDR:

- Adequacy of insurance coverage. Based on work by Bashshur et al. (Bashshur et al., 1993), Lurie defines underinsurance as “a situation in which the consequences of having less than full coverage are so burdensome that they inhibit realized access to needed care likely to result in the best possible outcome" (Lurie, 2002, p. 123). Lurie recommends presenting data on benefits, co-payments, and deductibles for different racial and ethnic groups by income. She maintains that assessing the adequacy of insurance coverage in this way would promote a more accurate analysis of the adequacy of insurance coverage than relying on a uniform standard of uninsurance that did not take into account the ability to afford out-of-pocket expenses.

- Language access. Millions of Americans have difficulty communicating in English. It is important that patients be able to clearly communicate their medical and social histories, symptoms, and concerns to their providers, and that providers be able to clearly communicate their questions, diagnoses, and recommendations for treatment (Lavizzo-Mourey and Mackenzie, 1996; Morales et al., 1999; Perez-Stable et al., 1995). New measures should be developed that address whether language access is available through either bi- or multi-lingual providers or trained interpreters and whether it is of adequate quality (California Pan-Ethnic Health Network (CPEHN), 2001). Frequently, language interpretation including American Sign Language is unavailable, leaving the task to volunteers, friends, and family. This can compromise privacy and free exchange of information (IOM, 2002b; Woloshin et al., 1995).
- Regular site of care and regular provider. Access to a regular source of care—whether to a particular site such as a local clinic or a particular provider such as a primary care physician—makes it more likely that individuals will receive a greater number of appropriate health care services. This in turn makes it more likely that individuals will experience better health outcomes (IOM, 2002a; Lurie, 2002).
- Access to mental health care. Racial and ethnic minorities are especially likely to have limited access to mental health care (DHHS, 2001). The dimensions of limited access that measures should capture include service availability and insurance coverage.

> Mental health therapy is especially dependent on communication and understanding between patients and providers (DHHS, 2001; Takeuchi et al., 1995). Therefore, measures of access should also indicate obstacles posed by racial, language, and cultural differences (CPEHN, 2001).

1–3. MEASUREMENT OF DISPARITIES IN HEALTH CARE SERVICES AND QUALITY

Health care disparities, including those in service utilization and quality, can be measured in absolute or relative terms. Measuring disparities in absolute terms means comparing the care received to evidence-based standards of quality. Measuring disparities in relative terms usually involves comparing the care that racial and ethnic minorities receive to the care that majorities receive. However, this is problematic if the care that majorities receive is not consistent with evidence-based standards of quality. For example, greater receipt of a particular kind of procedure may reflect health care overuse, which results in greater exposure to medical errors and other risks of needless treatment. AHRQ should explore the possibility of using an absolute standard of evidence-based quality care. This would imply that the NHDR would report on the proportions of those of different races and ethnicities that receive evidence-based quality care. At the same time, many areas of health care lack absolute standards of evidence-based quality care, which will limit the ability of the NHDR to rely on them.

While disparities usually describe care in which minorities receives *fewer* services or procedures, it is important for the NHDR to educate policy makers, consumers, and other audiences of the report about another kind of health care disparity in which minorities receive *more* services or procedures. However, this kind of disparity does not indicate that minorities are in these cases more likely to receive better health care. Instead, it reveals that minorities often received poorer prior care, necessitating more extreme and less desirable interventions.

4. The National Healthcare Disparities Report should include measures of high utilization of certain health care services that indicate poor

health care quality. It should also include measures of low utilization of certain health care services, which are more commonly used to indicate poor health care quality.

Research has revealed a number of health care services in which high minority utilization holds true (IOM, 2002b). For example, compared to Whites, African Americans with asthma are more likely to be treated in emergency departments and are more likely to be hospitalized, indicating poorer preventive and primary care (Zoratti et al., 1998). Compared to Whites, African American diabetics are more likely to receive amputations, again indicating poor prior care or lack of access to primary care services (Andersen et al., 1983). In mental health care, minorities in some cases receive more antipsychotic medications administered in emergency departments (Segal et al., 1996).

This kind of disparity stands in contrast to the more familiar kind that should also be featured in the NHDR. These occur when minorities receive fewer health care procedures than other races and ethnicities (IOM, 2002b; Mayberry et al., 2000). For example, it is the case that Whites were more likely than African Americans, Hispanics, and Asian Americans to receive coronary angiography, angioplasty, and coronary artery bypass graft (CABG) surgery. In addition, compared to African Americans, Whites were more apt to receive an effective range of diagnostic procedures for colon cancer as well as post-treatment surveillance care. Whites were also more likely to receive adequate pain medication for cancer (IOM, 2002b).

1–4. MEASUREMENT OF GEOGRAPHIC DISPARITIES IN HEALTH CARE

The NHDR should present national-level information on health care disparities. However, geographic data on health care is also available on subnational units that include states, counties, regions, ZIP code areas, primary care service areas, hospital service areas, rural and metropolitan areas, and census units such as tracts and block groups (Ricketts, 2002). While the number of geographic units is large, at least in the short term the NHDR should focus on states and rural and urban areas. However, in the future, policy trends, data availability, and other issues could suggest that the NHDR should also include analyses at smaller subnational levels.

> **5. The National Healthcare Disparities Report should present data on disparities at the state level. It should also present data on disparities along a rural-urban continuum.**

The NHDR should focus on states for two major reasons. First, states play important roles in health care and, by extension, must play important roles in any future efforts to eliminate health care disparities. States, for example, help to fund and primarily administer such programs as Medicaid and the State Children's Health Insurance Program (SCHIP). They are also charged with key public health activities such as data collection and reporting, prevention programs, and health care delivery. In addition, they carry out key regulatory and oversight functions that affect patients, providers, provider organizations, facilities, and insurers, among others (Ricketts, 2002).

Secondly, the NHDR should focus on states because they would interest the report's primary audiences, which consist of Congress, other policy makers, and consumers. Congress has indicated that it is a primary audience by mandating that AHRQ annually report to it on health care disparities, including geographic disparities. The IOM Committee on the National Quality Report on Health Care Delivery also identified other policy makers and consumers as the primary audiences for the NHQR (IOM, 2001c). It is likely that other policy makers and consumers will be primary audiences for the NHDR as well. Policy makers are increasingly interested in disparities issues and initiatives to eliminate them (Murray-Garcia, 2002; OMH [DHHS], 2002). At a time in which the nation is becoming more diverse, growing minority populations have registered increasing concern about disparate treatment.

The NHDR should also present information on rural and urban areas. Rural areas are strongly represented in Congress. In particular, in the Senate, rural states such as North Dakota and Wyoming have the same number of Senators as highly populous states such as California.

Urban areas also draw substantial interest in Congress, where they are more strongly represented in the population-based House. Both rural and urban health care disparities have long concerned Congress. It has supported a number of programs aimed at addressing issues such as physician supply and hospital and clinic support, and monitors the impact of programs such as Medicare and Medicaid on rural and urban health care delivery (MedPAC, 2001).

While the NHDR should feature information on geographic disparities featuring states and rural and urban areas, it should be noted that states and rural and urban areas are heterogeneous units. State comparisons can produce misleading results. For example, a large state with a racially and ethnically diverse population such as California faces very different challenges in health care delivery than a smaller state such as Vermont, which has a more racially and ethnically homogenous population. Similarly, comparing all rural areas with all urban areas can mask considerable differences within both. For example, rural Wyoming and rural Pennsylvania significantly vary in how far their residents are from major medical centers while urban areas significantly vary in the degree of access their residents have to health care. It can also be misleading to draw a dichotomy between rural and urban areas. Instead, there is a continuum of geographical areas that is defined by gradations in population density, distance from population centers and services, and other characteristics.

In addition to states and rural and urban areas, the NHDR could make use of such population-based measures as residential segregation, community impoverishment, and income inequality. Residential segregation has most often been measured using the dissimilarity index, which indicates the proportion of one group that would need to relocate from one community to the other to achieve an even distribution in both (Sakoda, 1981). Residential racial segregation has been linked to greater risk for infectious disease (Acevedo-Garcia, 2000), greater hospital segregation (Smith, 1998), higher Black infant mortality (Polednak, 1996), and higher all-cause mortality for Blacks and Whites (Acevedo-Garcia, 2000; Cooper et al., 2001; Jackson et al., 2000). Segregated Black communities have higher concentrations of toxic air (Lopez, 2002), fewer food stores (Morland et al., 2002), more liquor stores (LaVeist and Wallace, 2000), and fewer medical providers (Gaston et al., 1998; Williams and Collins, 2001).

Similarly, community impoverishment has been shown to affect coronary artery disease and cause mortality independent of individual-level risk factors (Anderson et al., 1997; Diez Roux et al., 2001; Waitzman and Smith, 1998). Income inequality, whether measured at the state or community level, has been linked to higher rates of violent crime (Kennedy et al., 1998); increased teen births (Gold et al., 2001); obesity (Kahn et al., 1998); and poor health (Fiscella and Franks, 2000; Lochner et al., 2001). Effects of income inequality may be improved to some extent by better access to primary care (Shi and Starfield, 2000; Shi and Starfield, 2001). Many of these indicators have been used with periodic national surveys such as the National Health and Nutrition Examination Survey (NHANES), the National Health Interview Survey (NHIS), and the Behavioral Risk Factor Surveillance System (BRFSS) and so could lend themselves to monitoring over time in the NHDR.

1–5. SUBNATIONAL DATASETS

A variety of datasets could help to supply the needs of the NHDR.[6] These include surveys produced by single states that have sizable racial and ethnic populations and subpopulations. In addition are surveys of all or multiple states, localities, or other entities in multiple states sponsored by public or private sources. Still others are nationally representative surveys, databases, or data-oriented reports that could also be useful for the NHDR. Table 1–1 contains the name of the datasets along with information on where to obtain further information on them.

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[6] The long-term data needs of the NHDR and other disparities-related programs and activities of the Department of Health and Human Services (DHHS) will be addressed in another study underway at the National Academy of Sciences. This study, which is being conducted by the National Research Council’s Committee on DHHS Collection of Race and Ethnicity Data, will examine data requirements and limitations and ways to improve data sources. It expects to issue a final report in late 2003.

TABLE 1–1 Possible Subnational Datasets to Support the National Healthcare Disparities Report (NHDR)

Dataset	**Responsible Organization**	**Website Address**
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention (CDC)	www.cdc.gov/brfss
California Health Interview Survey (CHIS)	UCLA Center for Health Policy Research, CA Dept. of Health Services	www.healthpolicy.ucla.edu/chis
Consumer Assessment of Health Plans (CAHPS)	Agency for Healthcare Research and Quality (AHRQ)	www.ahrq.gov/qual/cahps
Commonwealth Fund Health Care Quality Survey	Commonwealth Fund	www.cmwf.org
Community Health Status Report	Health Resources and Services Administration (HRSA)	www.communityhealth.hrsa.gov
Community Tracking Survey (CTS)	Center for Studying Health System Change	www.hschange.org
Hawaii Health Survey (HHS)	Hawaii Dept. of Health	www.hawaii.gov/health/stats/surveys/hhs.htm
Healthcare Cost and Utilization Project (HCUP)	AHRQ	www/ahrq.gov/data/hcup
HMO Research Network	AHRQ	http://hmoresearchnetwork.org
Medical Care Data Base	Maryland Health Care Commission (MHCC)	www.mhcc.state.md.us

Dataset	**Responsible Organization**	**Website Address**
Medicare Administrative Data	Centers for Medicare and Medicaid Services (CMS)	www.hcfa.gov/stats
National Survey of America's Families (NSAF)	Urban Institute	www.urban.org/Content/Research/NewFederalism/NSAF/Overview/NSAFOverview.htm
Peer Review Organization Data	CMS	www.hcfa.gov/stats
Proprietary Health Care Databases	MEDSTAT Group	www.medstat.com
State Health Facts Online	Kaiser Family Foundation (KFF)	www.statehealthfacts.kff.org
State Surveys on Health Insurance Coverage	State Health Access Data Assistance Center (SHADAC)	www.shadac.org

There are advantages and disadvantages to the use of subnational datasets in the NHDR, on which AHRQ plans to rely at least in the short term (Burstin, 2002). Their primary advantage lies in the samples of subpopulations that some contain and that currently are inadequately represented in national datasets. For example, the new California Health Interview Survey (CHIS) provides estimates on such aspects of care as insurance coverage, access, and barriers to health services for the major racial and ethnic populations in the state. It also provides estimates for smaller subpopulations, including Asian American and Pacific Islander ethnic groups, American Indians, and Alaska Natives.

AHRQ should take into account the following methodological considerations in using subnational datasets:

- Sampling designs. While racial and ethnic minority populations have grown significantly over the past two decades, they remain a relatively small proportion of the total population in many communities. In studies of small populations, certain sampling decisions must be made to decrease cost and increase survey efficiency. However, these decisions can limit the extent to which conclusions can be drawn about the target population. For example, a study of Chinese Americans in Los Angeles County lowered screening costs by restricting its sampling frame to geographic areas (census tracts) where Chinese Americans comprised at least six percent of the population (Takeuchi et al., 1998). The six percent criterion provided coverage of approximately sixty percent of the Chinese American population in Los Angeles. At the same time, it limited the extent to which conclusions can be drawn about all Chinese Americans living in Los Angeles since it excluded Chinese Americans in low density Chinese American geographic areas, who tend to be native born and more prosperous.
- Translations. Immigrants comprise a substantial proportion of Asian Americans and Latinos. Since many immigrants may not speak English, it is important to know whether respondents were offered translated versions of survey questionnaires. If a region has a sizable number of immigrants and translated versions of a questionnaire were not provided, this limits the extent to which results can be generalized to all members of a group.
- Response rates. Survey response rates have declined, especially in major urban areas. It is critical to know the response rate for subnational data sources and, if possible, for different racial and ethnic minority groups. Lower response rates can limit the generalizability of survey findings.

AHRQ and other governmental entities have productively worked with private entities in the past to develop and disseminate health care measures. Public and private utilization of the Consumer Assessment of Health Plans (CAHPS) is a major example of this kind of partnership. AHRQ could work with public and private organizations that sponsor key subnational data sources to help make these data sources more useful for the NHDR. These data sources could shed light on how race, ethnicity, socioeconomic status, and geography affect health care. For example, very little is known about the health care of Native Hawaiians and Pacific Islanders. Since a major proportion of Native Hawaiians and Pacific Islanders lives in California and Hawaii, it may be advantageous for AHRQ to work with sponsors of subnational data sources in these states to address issues of race, ethnicity, and health care. Public and private organizations would also realize advantages from this partnership. It is likely that datasets compatible with the NHDR would also be more useful as separate data sources or as data sources used in conjunction with others.

> **6. In the future, if AHRQ continues to rely on subnational data sources for the National Healthcare Disparities Report, it should work with public and private organizations that sponsor key subnational data sources to identify core elements in these surveys that can be standardized.**

More specifically, AHRQ and other organizations must address the fact that subnational datasets measure core elements such as race, ethnicity, and socioeconomic status in ways that differ from each other and differ from many national datasets. For example, race and ethnicity are measured in several ways. Federal policy for national surveys calls for respondents to have the option of selecting multiple races or, in the case of ethnicity, Hispanic or Latino or Not Hispanic or Latino. However, some subnational surveys require respondents to choose only one racial category. The question that is used in a survey will affect the size of the denominator and therefore estimates of the prevalence of what is being measured. It will also influence the extent to which generalizations can be made about racial and ethnic communities. In addition, subnational surveys and other data sources differ on whether racial and ethnic identities are reported by respondents or by observers.[7]

Standardized measurement of socioeconomic status is also lacking. For example, the way that respondents are asked to estimate

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[7] Studies indicate that self reporting is more accurate (Williams, 2001).

their incomes can differ. Most ask respondents to place themselves within specified earning ranges that differ in size. However, they use the general concept of “earnings” without distinguishing wage and salary earnings from investment earnings so that there is uncertainty about what is being reported.

There are ways to address at least some of these differences. For example, AHRQ could provide leadership on the measures of socioeconomic status that are most useful for explaining disparities in health care. It could also work with public and private organizations to develop measures of socioeconomic status that can be supported by data that are feasible to collect for a range of surveys. The agency could also support longitudinal efforts, which allow health status to be measured before health care is utilized rather than at the same time. This makes it possible to draw stronger inferences about the causes behind racial, ethnic, socioeconomic, and geographic disparities in health care. Many subnational datasets are derived from cross-sectional surveys that provide detailed information about specific racial or ethnic groups or about specific geographic areas. AHRQ could explore ways to encourage or support conversion of some of these cross-sectional surveys into panel studies that would follow respondents over time. In any relationship AHRQ develops with other sponsors of subnational datasets, it should be remembered that agency policies are to an extent determined by federal policy. For example, AHRQ does not have the authority to formulate racial and ethnic categories that differ from those in OMB Directive 15. In addition, there are technical issues associated with subnational datasets that will be difficult to resolve for financial, administrative, and other reasons. For example, different datasets rely on different methods to determine the size of the subpopulation in question, which can produce varying estimates of prevalence and which also can affect estimates of the success of particular interventions.

1–6. GENERAL ISSUES

Several general issues apply to the NHDR as a whole or to some or all of its topic areas in measurement and data source development, including the criteria that should guide the development of new measures for the NHDR. They include the importance of providing measures that policy makers, consumers, and others would find readily understandable. Measures should indicate areas in which policy makers can target legislative or other action to eliminate disparities.

AHRQ should rely on the criteria for measurement development identified by the Committee on the National Quality Report on Health Care Delivery (IOM, 2001c, pp. 82–7). More specifically, measures should be:

- *Important,* as indicated by their relationship to health status and relevance to policy makers and consumers;
- *Scientifically sound,* as reflected by their validity, reliability, and substantiation; and
- *Feasible,* as indicated by current use or prototype development, data availability (including data for subpopulation analyses), and expense and difficulty of gathering the data.

Applying these criteria, for example, could mean that the NHDR should rely on measures for conditions such as hypertension that are highly prevalent and/or that pose a substantial health burden in minority populations, as do cancer and end stage renal disease. It could also mean that the NHDR should focus on populations who have conditions with clinical needs that are well defined. This would include diabetics who need eye examinations and patients with histories of myocardial infarction who need beta blockers. In addition, it could mean that disparities highlighted in the NHDR should be related to national goals for health care specified in *Healthy People 2010* such as access to clinical preventive care, emergency services, and long term care and rehabilitative services (DHHS, 2002).

As noted above, AHRQ will need to develop new measures in the areas of health care access, service utilization, and quality if the NHDR is to fulfill its potential of becoming a new and important government report on the nation’s health care disparities and a critical tool to help guide action on their elimination. In addition, the agency will need to develop new measures for both the NHQR and the NHDR that can cover components of their common framework, such as safety, for which few measures currently exist (IOM, 2001c; Lurie, 2002). Both new and current measures of health care disparities will in turn require data on race, ethnicity, socioeconomic status, and geography that can support them.

7. AHRQ should receive adequate resources to develop datasets and measures needed for the National Healthcare Disparities Report.

AHRQ has the responsibility of ensuring that the measures and datasets needed for the NHDR are developed. The exact nature and amount of resources that the agency will require are beyond the scope of this report. However, AHRQ will need expertise and substantial means to develop measures on access, service utilization, and quality that can meet the criteria of importance, scientific soundness, and feasibility. To do so, the agency will have to formulate and evaluate measures based on their scientific soundness and feasibility; solicit input from providers, patient groups, and others on measurement development and evaluation; and reexamine the measure set and its ability to reflect changes in the health care system and the nature of health care disparities (IOM, 2001c). AHRQ also faces a number of challenges in obtaining the data necessary to support the report. While there are a number of datasets available, each has real limitations that the agency must develop strategies to address.

The NHDR should not devote attention to the impact of behavior such as attitudes toward health on health care disparities. The contribution that personal attitudes make can be difficult to interpret, and many areas in which disparities occur do not involve patients' personal attitudes. Certainly, attitudes can make a difference in those areas of health care that depend on individual initiative or discretion, such as seeking the preventive care that insurance covers and complying with providers' instructions. However, in many of these areas, individual initiative or discretion can be more constrained than might first appear to be the case. For example, seeking preventive care that insurance covers can be more difficult when time off from work is limited and access to transportation is uncertain (Heckman et al., 1998; Heymann, 2000; Lannon et al., 1995; Perloff et al., 1997). Complying with providers' instructions can be more difficult when literacy is a problem or when health insurance is lacking or does not fully cover the recommended treatment.

Should the NHDR only devote attention to matters under the direct influence of the health care system? As defined by the Committee on the National Quality Report on Health Care Delivery, these matters refer to "care that can be influenced by the health care system as it exists or as it is envisioned" (IOM, 2001c, p. 84). To elaborate, those in rural areas are more likely to die from car accidents (Ricketts, 2002). Although the health care system can seek to improve trauma care, many policy responses such as speed limits, road design, and car design fall outside of its purview. The NHDR should mainly, but not exclusively, address issues that the health care system could directly affect. It is appropriate for AHRQ to make health care quality and the quality-related performance of the health care system an important focus of the NHDR as well. However, disparities are inextricably related to issues that fall outside of the primary influence of the system such as the availability of public and private transportation (IOM, 2001a; IOM, 2002a; IOM, 2002b; Lurie, 2002). Therefore the NHDR should address these disparities too. For example, the report could include data on disparities in reliance on public transportation, which can make timely treatment difficult for those in rural and inner city communities.

The NHDR will change and improve over time. For practical reasons, it is likely that in the short term AHRQ would make use of current measures and data sources on racial, ethnic, socioeconomic, and geographic disparities in the early editions of the report. However, with time and adequate resources, AHRQ will have the opportunity to introduce more specific measures for use in later editions that will more accurately detect the magnitude of health care disparities. Measures could be drawn from those used in the NHQR that are particularly relevant to racial, ethnic, socioeconomic, and geographic disparities. These include measures of areas with unusually large disparities; those likely to result in death or serious illness; or those susceptible to improvement. Because of space limitations, AHRQ will monitor a larger set of measures than it can include in the NHQR.

Measures in this larger set could be used in the NHDR if they are more pertinent to disparities. Also, measures of disparities in health care service utilization and quality described by LaVeist (LaVeist, 2002) and measures of disparities in access described by Lurie (Lurie, 2002) could be used in the NHDR.

Lastly, the design and dissemination of the NHDR will be critical to the report's success. A design that does not appeal to the report's audiences will discourage them from reading it, using it as a reference source, and recommending it to others. Poor dissemination will mean that fewer people will learn about it, with the result that its annual updates on health care disparities will not have the impact that they should. The design and dissemination strategies for the NHQR developed by the Committee on the National Quality Report on Health Care Delivery (IOM, 2001c) are sound approaches that could in general be applied to the NHDR as well.

1–7. CONCLUSION

It is important to accurately identify the disparities that are primarily racial and ethnic and those that are primarily socioeconomic. Therefore, the NHDR should present findings on racial and ethnic health care disparities that reflect the impact of socioeconomic status. Also, there is currently an inadequate understanding of the relationship of socioeconomic status to health care. AHRQ should initiate research on the relationship with the goal of producing more useful, accurate, and meaningful measures of socioeconomic status.

The NHDR should include measures of high utilization of certain health care services, such as greater minority use of emergency department care, that may indicate poor access to care or quality of care. To increase interest in the report by policy makers, consumers, and other key audiences, the NHDR should present data on disparities by state and by urban and by rural areas. Also, if the NHDR draws from subnational data sources in the long term, AHRQ should collaborate with data source sponsors to identify core elements in these surveys that can be standardized.

AHRQ has the opportunity to make the NHDR a valuable and effective tool for eliminating racial, ethnic, socioeconomic, and geographic disparities in the nation's health care system. To take advantage of this opportunity, AHRQ should receive adequate funding and resources to develop the datasets and measures that will be needed for the report.

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2

MEASURING THE EFFECTS OF SOCIOECONOMIC STATUS ON HEALTH CARE

Marian E.Gornick

The primary purpose of this paper is to consider ways of operationalizing and assessing the effects of socioeconomic status on health care for the National Healthcare Disparities Report (NHDR). To study the effects of socioeconomic status on health care, researchers have "borrowed" some of the methods used by social scientists in studying its effects on health without systematically examining how suitable they are for this task.[1] This paper will review these methods to determine if they are applicable and appropriate for studying disparities in health care.[2] In addition, this paper includes race and ethnicity in relevant discussions about disparities in health care. In the past, race was used in studies about disparities in health care mainly because data for race were available, although race was often seen as a proxy for income. Now, race and ethnicity are used as independent variables in studies of disparities in health care.

The first two parts of this paper focus on socioeconomic status and health. The second two parts focus on socioeconomic status and health care. Part 2–1 contains a brief history of the framework developed by social scientists to study the effects of socioeconomic status on health, and Part 2–2 presents an overview of the current methods that social scientists use in studying socioeconomic status and health. Part 2–3 presents an overview of the current methods that health services researchers use in studying disparities in health care.

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[1] Instead of socioeconomic status, some social scientists use the concept of socioeconomic position, which they believe takes into account more of the social and economic factors that influence health.

[2] Researchers use the expression "disparities in health care" while social scientists tend to refer to disparities in health as "inequalities in health."

Several tabulations are provided to illustrate the approaches and data sources that have been developed to study disparities by race, ethnicity, and socioeconomic status. Part 2–4 presents an overview of common data issues in studies of health care disparities.

2–1. STUDYING THE EFFECTS OF SOCIOECONOMIC STATUS ON HEALTH

Since 1985 there has been a substantial increase in the number of studies about the relationships between socioeconomic factors and health. In an article published in 1999, Nancy E.Adler and Joan M. Ostrove sketched the evolution of the theoretical framework now used in studying disparities in health (Adler and Ostrove, 1999). Before the mid-1980's, socioeconomic status was largely absent in studies on health except as a control variable. Studies focused on poverty and its association with health. The model assumed a threshold effect: the health of people below the poverty level was believed to improve as their income increased and reached the poverty threshold. Above the poverty threshold, the level of health was constant as income increased.

At a 1987 conference sponsored by the Kaiser Family Foundation, leading social scientists from the U.S. and Great Britain presented a number of papers that showed that the effect of socioeconomic factors was much broader than just poverty. In fact, many social and economic factors are related to health. Moreover, there is a gradient effect between socioeconomic status and health: as socioeconomic status increased, health improved. The conference resulted in the 1989 publication of *Pathways to Health* (Bunker et al., 1989).

The papers were groundbreaking and ushered in an era of profound intellectual and pioneering work to understand the effects of socioeconomic status on health. A reading of *Pathways to Health* today shows that the 1980 Black Report[3] (Black, 1982) stimulated the

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[3] The report is commonly referred to as the Black Report after Sir Douglas Black, chair of the Research Working Group, Department of Health and Social Security, U.K..

thinking of many social scientists because it had found that gaps in health had widened since the establishment of the National Health Service in 1948. The Black Report became the underpinning of the belief that health care does not play a very important role in health. Robert and House describe the prevailing views of social scientists during the 1980s and 1990s:

> Most research suggests that access to medical care plays a relatively minor role in explaining socioeconomic inequalities in health…socioeconomic differences are seen both in diseases that are amenable to medical treatment and in diseases that are not amenable to medical treatment …with deaths from diseases amenable to treatment representing only a fraction of all deaths in any case (Robert and House, 2000, p. 121).

These conference papers also may have encouraged the development of models that would focus on the effects of socioeconomic status on health without inclusion of race as an independent variable. The likely premise has been that racial differences in morbidity and mortality are reflections of differences in social and economic factors. However, in recent years social scientists have noted that "studies may need to address how class-related experiences of racial/ethnic and gender discrimination may harm health" (Krieger et al., 1997, p. 369).

2–2. REVIEW OF METHODS USED IN STUDYING THE EFFECTS OF SOCIOECONOMIC STATUS ON HEALTH

The following is an overview of the methods that social scientists use in studying the effects of socioeconomic status on health to determine what is applicable to studying the effects of socioeconomic status on health care. Cross-fertilization of knowledge between social scientists and health services research promises to be beneficial all around. The dissemination of information about disparities in the use of Medicare services has helped to change the perception that health insurance by itself assures equal access and use of health care (Robert and House, 2000). An example of the beneficial effects of cross-fertilization of knowledge from social scientists—and one that is central to this paper—is the recent recognition by researchers that socioeconomic status is an important variable in studying disparities in health care, particularly disparities by race and ethnicity.

There is no simple conclusion or overwhelming agreement on the causes of disparities in health, reasons for growing gaps in health, ways to address them, or even how to study the issues. As Robert and House observe, "we still do not well and consensually understand why socioeconomic inequalities in health exist and persist, nor what policies are most likely and necessary to reduce these inequalities" (Robert and House, 2000, p. 115).

Nonetheless, a significant body of knowledge is available from studying the effects of socioeconomic status on health that is useful in studying the effects of socioeconomic status on health care. Four major issues on which a consensus has been reached are discussed next:

1. Is There a Single Best Approach to Measuring or Analyzing Socioeconomic Status?

The field of research about the effects of socioeconomic status on health (sometimes termed health status or health outcomes) is still new. The link between socioeconomic status and health is not well understood. Among social scientists there is a consensus that there are many different pathways connecting socioeconomic status and health. This means that a broad perspective is needed to understand the multiple pathways linking socioeconomic status and health.

This literature addresses two fundamental questions about methods of study: first, among the variables used as measures of socioeconomic status, is there a single best measure? Secondly, are some approaches used to analyze the effects of socioeconomic status better than others? The answers are, in general, "No." There are inherent imperfections and limitations in all of the measures of socioeconomic status just as there are in measures of race and ethnicity. But, when used thoughtfully, each measure can have its own ring of truth.

Research about socioeconomic status and health began to gain momentum in the mid-1980s. While much has been learned, frequently lacking in research is a clear conceptualization of what is being studied and why a particular measure of socioeconomic status is used. In fact, measures and methods are at times chosen because of data availability rather than because of theoretical premises. For example, in the U.K. occupation is used more frequently in studies about disparities in health. In the U.S. income and education are used more frequently. These choices are due, in part, to the type of social and economic information collected.

Recently, the use of composite measures has gained attention. Different composite measures of deprivation relating to material and social disadvantage have been developed for studying the effects of socioeconomic status on the individual and area levels (Pampalon and Raymond, 2000). Composite indices are generally constructed by combining information (often from a national census) about factors such as income, employment, communications, transportation, support, education, owned home, and living space. Peter Townsend (Townsend, 1987) and Morris and Carstairs (Morris and Carstairs, 1991) in the U.K. introduced composite indices for area-level analyses based on four factors. Three factors in both of the indices are unemployment, lack of a car, and overcrowded housing. For the fourth factor the Townsend index uses home ownership while the Carstairs index uses lower social class.

A different formulation of a composite index (named CAPSES) has been developed based on the theory that socioeconomic status is a function of three domains of capital: material capital (such as incomes, homes, and stocks); human capital (such as education, skills, and abilities); and social capital (such as membership in social networks).[4] A recent pilot study testing CAPSES against individual and other composite indices of socioeconomic status showed

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[4] CAPSES is an acronym formed from the words capital and socioeconomic status (SES).

considerable consistency across the various socioeconomic status measures (Oakes and Rossi, forthcoming).

Composite indices for area-level analyses have been used in different ways. They may be particularly useful as area-wide planning tools. For example, in the 1960s, the Planning Department in Baltimore City designed a composite index for census tract areas based on several social and economic factors. The index was used to rank census tracts from the most advantaged to the most deprived. For an experimental program set up in Baltimore in the 1970s, these rankings were used to establish a health program for children and youth in census tract areas that were most deprived.[5]

A Quebec study provides some insight into the potential difficulties in interpreting results of area rankings from a composite index of deprivation. Comparisons between area rankings and factors used in the index showed that areas deprived socially were not necessarily deprived materially and vice versa. Thus, the Quebec study provides a cautionary note that "lumping" socioeconomic status measures together can be confounding because the index does not necessarily provide a measure of area-level socioeconomic status that can be readily interpreted.

In their review of methods used in studying socioeconomic status and health, Robert and House conclude that questions about which measures and methods to use "remain unanswered and perhaps unanswerable in a generic sense" (Robert and House, 2000, p. 8). Moreover, there are many remaining methodological problems relating to studying the effects of socioeconomic status on health. These problems include:

1. The lack of precision and reliability of various measures as well as difficulties in generating measures of socioeconomic status;
2. Unresolved questions about how to measure the effects of socioeconomic status over the life course that would reflect change in social and economic factors from birth to old age;

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[5] From personal participation in the Baltimore City Health Department study.

3. Some measures of socioeconomic status that are useful for studying their effects within some races and ethnic groups may not be useful for other races and ethnic groups, a methodological issue that also applies to gender;
4. A lack of understanding about why the relationships between socioeconomic status and health are stronger for men than for women;
5. Difficulties with classifying married women, the unemployed, and retired persons in a household;
6. Difficulty of including mental and other psychosocial factors that affect health in measures of socioeconomic status; and
7. The intertwining of race, ethnicity, and socioeconomic status, and how to assess the separate effects.

The list of unresolved conceptual and measurement questions is long although the viewpoint of experts such as Krieger, Williams, and Moss is clear about certain issues: “we underscore the issue is not whether one measure is ‘right’ or another ‘wrong’…rather, numerous studies suggest that measures at each level, over time, may be informative, separately and in combination” (Krieger et al., 1997, p. 349). They add that “the utility of socioeconomic indices for public health research remains unclear…. One concern is that combining measures of income and education into one index…can conflate pathways and obscure each component’s distinct—and conceivably different—contribution to specified health outcomes” (Krieger et al., 1997, p. 366).

This overview of methods used to study the effects of socioeconomic status indicates that there is no one right measure. The choice of a “right” measure depends upon the study. Table 2–1 briefly summarizes the advantages and disadvantages of using specific measures of socioeconomic status.

2. What is the Relationship between Socioeconomic Status and Health?

The direction of the relationship between socioeconomic status and health is a fundamental issue in understanding pathways leading to disparities in health. While some economists believe that health drives socioeconomic status —because poor health has a negative effect on job opportunities and socioeconomic position (social drift)—most social scientists believe the direction of the relationship is the other way around. Among those who have studied disparities in health, there is a consensus that biological and genetic differences account for a relatively small proportion of the disparities in health. Supporting that belief is a study of the effects of six risk factors—smoking, alcohol consumption, systolic blood pressure, cholesterol level, body mass index, and diabetes. The study showed that these six factors together accounted for only 31 percent of the difference in mortality between Blacks and Whites. Income accounted for 38 percent of the difference in mortality, while the remaining 31 percent of excess mortality among Blacks was unexplained (Otten et al., 1990).

Among those who have studied disparities in *health care,* there is also a consensus that biological, genetic, and health status differences account for very little of the persistent disparities by race in health care. For example, one study found that Black veterans with coronary artery disease were 64 percent less likely than White veterans to undergo coronary artery bypass graft (CABG) and balloon angioplasty (Peterson et al., 1994). Several other studies in the literature have found disparities by race in the use of revascularization procedures (Ayanian et al., 1993; Udvarhelyi et al., 1992; Wenneker and Epstein, 1988; Whittle et al., 1993). However, because certain diseases such as hypertension, diabetes, and osteoporosis are not uniformly distributed in the population, such differences must be recognized because they can lie at the crux of the credibility of studies about disparities in access, utilization, and quality of health care. For example, differences in amputations of all or part of the lower limb must be examined in light of differences in diabetes (Gornick et al., 1996).

TABLE 2–1 Summary of Measures of Socioeconomic Status: Methodological Advantages and Disadvantages

ADVANTAGES	**DISADVANTAGES**
Income from Surveys	
Household income a generally accepted measure. Three or more categories preferred, but cell sizes may permit only two.	May not be a fully logical measure for persons with insurance, especially if service does not require cost sharing. May not be able to adjust for family size.
Income, from U.S. Census Data	
Median household income in ZIP code a generally accepted measure. Median income in ZIP code a proxy for individual income. Reflects characteristics of area of residence and may indicate availability of resources.	Smaller areas such as census tracts preferable, but only 70 percent of addresses in census tracts. Cannot be adjusted for family size.
Education	
Comments about income generally apply to education. But education may be a more coherent measure, especially in assessing use of services such as preventive services, which are often self initiated.	Surveys that contain education for household head may not be valid measure for other members. From census data, education and income not statistically valid when used together in multivariate analyses because of multicollinearity.
Poverty Level	
Can be a more sensitive economic measure than income, suggesting how Medicaid affects access and utilization.	Not as readily accepted by public because of concerns about what the levels mean.
Occupation	
An important measure in U.K. because information collected about occupation.	Could be used in studies based on household surveys. In census data, summary measure of occupation not available.
Wealth	
A useful measure for analyzing access to costly services not generally covered by insurance, such as nursing home care.	Not a commonly used measure for services covered by insurance.
Composite Indices	
Composite indices may be useful, adding context. The CAPSES scale has been found consistent with other measures of socioeconomic status.	A summary measure must be used cautiously. Could be difficult to interpret because it combines several measures of socioeconomic status.

3. Should Socioeconomic Status Be Used as a Primary Independent Variable to Analyze Health Outcomes?

Social scientists ceased using socioeconomic status as a control variable when they recognized that health was affected not only by poverty, but also by a much broader set of variables including income, education, and occupation. Thus, if the intent is to understand factors that affect disparities in access, utilization, or quality of care, socioeconomic status should not be used as a control variable.

This is critical to studying the effects of socioeconomic status on health care, especially in relatively new areas of research. For example, suppose it were found that on average highly educated people rate health plans better than less educated people. It could be hypothesized that this consistent pattern biases the ratings, and therefore controlling for education across plans is warranted. However, better-educated members of a plan may get better health care if their interactions with the plan are more successful. For example, they may experience less waiting time for appointments or they may be more successful getting referrals to specialists than less educated members of the plan (Fiscella et al., 2000).

4. Why Does Research on Disparities Require a Clear Conceptualization?

Ameliorating disparities in health care requires a conceptual framework that evolves from hypothesis testing, especially those hypotheses that can help pinpoint potential agents of change. For example, a framework might first evolve from formulating hypotheses about how individuals and the health care delivery system interact in terms of behaviors of individuals, providers, and institutions. This would be followed by testing how these interactions are associated with access, utilization, and quality of care. Behaviors have been shown to be factors associated with disparities in the use of preventive services because these services are often self initiated (Gornick et al., 2001; Lemon et al., 2001).

As an example, elderly women with higher incomes and supplementary insurance are more likely to obtain mammograms than lower income women and women without additional coverage. Under Medicare, mammography requires a co-payment, which suggests that the co-payment may lead to the disparities associated with income. In every insurance category—Medicare only, Medicaid, and private supplementary coverage—mammography use rises with income (Blustein, 1995). Yet, there are even greater disparities in the use of flu shots, which are "free." These facts do not rule out the effect of income, but they do suggest that there are likely to be multiple pathways leading to disparities in utilization.

2–3. REVIEW OF METHODS USED IN STUDYING DISPARITIES IN HEALTH CARE

Disparities in health care have been studied for many years. For example, before the advent of Medicare it was known that the elderly who were minorities and who were poor received inpatient hospital care at a much lower rate than Whites and more advantaged persons. Early studies focused primarily on known "barriers to care." Lack of health insurance and a regular source of health care were identifiable obstructions to obtaining health care. When these barriers were removed and the elderly and the poor could enter the health care system, it was expected that there would be equal access to covered services and that the use of any particular service would reflect need. In the past decade, disparities in Medicare have led to the awareness that there are other barriers to health care that are related to race, ethnicity, and socioeconomic status.

We do not know how great a role medical care plays in explaining disparities by race and socioeconomic status in health and health care. What is known is that patterns of health care utilization among the healthiest elderly differ from those of the least healthy. Moreover, the patterns of health care use among the healthiest are those that experts recommend, specifically a concentration on prevention and health promotion. In the Medicare program, three distinct patterns have become evident. Compared to Whites and beneficiaries (White or Black) of higher socioeconomic status, Blacks and beneficiaries (White or Black) of lower socioeconomic status use fewer preventive and health promotion services such as influenza immunization and mammography. They also use fewer diagnostic tests such as colonoscopy and undergo fewer common surgical procedures such as CABG. In addition, they use more of the types of procedures that are associated with poor management of chronic disease such as excisional debridement and amputations of part or all of the lower limb (Gornick, 2000).

Three principal approaches are used to study the effects of race, ethnicity, and socioeconomic status on access, utilization, and quality of care. The first approach uses information about health care collected in nationally representative household surveys. The second draws from administrative databases from such sources as the Medicare and Medicaid programs, the Veterans Administration, and hospital discharges. The third is based on clinical data collected by sources such as medical records and disease registries.

The detailed data collected about health care in surveys of nationally representative households provide a rich source of information to study the effects of race, ethnicity, and socioeconomic status (income and education) on potential access. This is the dimension of access to care that is measured by characteristics of individuals and of the health care system (Aday et al., 1984). Measures of potential access most often used include health insurance coverage and a regular source of care. Other measures of potential access include availability of resources such as physicians-to-population ratios, hospital beds per capita, out-of-pocket costs of services, and waiting and travel time. Household surveys such as the Medical Expenditure Panel Survey (MEPS), sponsored by AHRQ, and the Medicare Current Beneficiary Survey (MCBS), sponsored by the Centers for Medicare and Medicaid Services (CMS), focus on collecting different measures of potential access. A special strength of survey data is that utilization rates are not subject to inaccuracies created by multiple payers. However, health care services that are less common, such as heart procedures, cannot be analyzed using survey data because of small cell sizes. In addition, the extent to which self reporting biases estimates of disparities in health care is not well understood.

A second approach is through information about "realized access" that is available in administrative databases. Realized access is measured by the actual use of services (Aday et al., 1984). Assessing the effects of socioeconomic status on realized access requires information about the use of different types of services such as those for health promotion and disease prevention, referral (including diagnostic tests and surgery), pain management, mental health, aftercare and rehabilitation, and long term care. The sample size of household surveys is generally large enough to generate utilization rates for frequently used services, such as influenza immunization and mammography, but not for less frequently used services such as CABG surgery. Data sources that collect information for a large number of people such as administrative data, surveys of hospital discharges, or statewide hospital discharge systems are needed to generate utilization rates for the majority of medical and surgical services. Both aspects—potential access and realized access—are essential dimensions in assessing access to care.[6]

The major strength of administrative data is the size of the files, which is often large enough to develop population-based utilization rates for many different types of services. A major limitation of administrative data is the inadequate information about race and ethnicity and the lack of clinical information about the need for certain services such as a particular heart procedure. In addition, administrative data typically do not contain enough detail to assess appropriateness or effectiveness. For example, administrative data capture whether a certain test was performed, but not the results of the test.

A critical factor in the use of administrative data is whether reliable information is available to generate denominator data that correspond to the numerator data. In general, denominators can be generated using Medicare, Medicaid, and VA administrative data. Over time, programmatic changes such as the growth of managed care

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[6] The term "access" is commonly used to refer to "potential access" to health care, which can be indicated by, for example, having health insurance coverage or a usual source of care. For ease of discussion, this paper conforms to the commonly accepted practice of using the phrase "access and utilization" to mean potential and realized access.

enrollment can threaten the reliability of administrative data, although analysts have devised ways of adjusting numerators and denominators for enrollment in health maintenance organizations (HMOs). However, in many cases, the relevant denominators for research on topics such as the number of persons by race for whom a procedure is indicated can only be determined by using selected patient-based studies.

To address the absence of data on socioeconomic status, Medicare data were linked in 1995 to U.S. census data on a ZIP code basis to study the effects of race and socioeconomic status on health care. This approach is derived from studies that validated the use of aggregate data on socioeconomic status from the census as a proxy for the socioeconomic status of an individual. This is based on the understanding that the proxy measure of socioeconomic status reflects both the characteristics of the individual and the area where the individual lives (Geronimus et al., 1993; Geronimus et al., 1995; Krieger, 1992). The match was incomplete for 4 percent of White beneficiaries and 6 percent of Black beneficiaries because of unmatched ZIP codes or missing income data on the census files. These beneficiaries were excluded from the study. The MCBS was used to validate this approach (Gornick et al., 1996). It was intended that the ZIP code analyses would be refined in future studies by using census tracts aggregations. However, that approach was abandoned for methodological reasons, including the fact that about 30 percent of addresses in the U.S. do not have a census tract.

A third approach is through patient-based studies to analyze treatments and quality of health care vis-à-vis patient need for medical and surgical care. The strength of patient-based studies is that they generally draw upon data sources containing clinical information, such as hospital medical records. One limitation in patient-based studies is that they are not likely to be nationally representative. Moreover, they do not reflect the population at risk of needing the treatment. Nonetheless, they are a rich source of information for analyzing quality of care. A number of patient-based studies have used a database established from the linkage of information available in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program with information available in the Medicare administrative data system. The SEER/Medicare database has also been linked to U.S. census data on a ZIP code basis. This has resulted in a unique source of information for studying the effects of race and socioeconomic status on disparities in the incidence and treatment of cancer, the second leading cause of death in the U.S..

These three approaches to studying disparities in health care have provided a wealth of information about the relationships among race, ethnicity, and socioeconomic status. It is important to note, however, that results are likely to differ somewhat according to the data source. For example, Medicare utilization data from the administrative data system reflect the experience of beneficiaries receiving services in the fee-for-service sector, whereas utilization data from the MCBS reflect the experience of all beneficiaries. Therefore, analysts need to be aware of the design features as well as the limitations and strengths of their data sources. The following tables illustrate the types of data available from household surveys and administrative data.

Table 2–2 also illustrates the gradient effect: as income increases, ambulatory visits and mammography rates increase. The gradient effect is in the opposite direction for emergency department visits and for amputations. The Black-to-White ratio of the rates for each service is shown at the bottom of Table 2–2, unadjusted and adjusted for income. The Black-to-White ratio for ambulatory visits— when adjusted for differences in income—rose from 0.89 to 0.93. Similarly, for mammography, the Black-to-White ratio rose from 0.66 to 0.75. For emergency department visits, the Black-to-White ratio improved slightly, declining from 1.45 to 1.37. Amputations had the same pattern, declining from 3.64 to 3.30.

TABLE 2–2 Rates for Selected Medicare Services, Age 65 Years and Over, by Race and Income, 1993

Race and Income	Ambulatory Physician Visits per Person	Emergency Dept. Physician Visits per 100 Persons	Mammograms per 100 Women	Amputation of All or Part of Lower Limb per 1,000 Persons
White Beneficiaries				
Total	8.1	35.0	26.0	1.9
$20,501 and over	9.0	29.6	31.0	1.5
$16,301 to $20,500	8.3	34.6	27.2	1.8
$13,101 to $16,300	7.6	36.8	24.1	2.1
Less than $13,101	7.3	39.9	20.8	2.0
Black Beneficiaries				
Total	7.2	50.6	17.1	6.7
$20,501 and over	8.0	44.2	20.4	5.8
$16,301 to $20,500	7.4	45.8	19.9	5.9
$13,101 to $16,300	7.7	52.2	21.0	6.1
Less than $13,101	7.1	51.6	16.0	7.0
Black/White Ratio, Unadjusted	*.89*	*1.45*	*.66*	*3.64*
Adjusted For Income	*.93*	*1.37*	*.75*	*3.30*

SOURCE: (Gornick et al., 1996; HCFA, 1995).

The lower bank of data shows generally similar patterns, but the percentages using the preventive services are generally lower. The rates differ because the number of women in the income and education groups changes somewhat. For example, among White women, the proportion of those in the higher income group (28.8 percent) was only about half the proportion of those in the higher education group (65.9 percent). Among Black women, the shifts are greater: 7.2 percent were in the higher income group while 36.0 percent were in the higher education groups.

TABLE 2–3 Percent of Women Receiving Mammography, Flu Shots, and Pap Smears, 65 Years of Age and Over, 1998

	WOMEN		**SERVICES**		
Race, Income, and Education	Number (in 1000s)	%	% with Mammogram	% with Flu Shot	% with Pap Smear
By Income					
Total-White	16,059	100.0	47.5	69.7	34.2
$25,001 and over	4,625	28.8	60.0	74.4	45.8
$25,000 or less	11,434	71.2	42.3	67.8	29.5
Total-Black	1,538	100.0	43.7	51.4	30.2
$25,001 and over	111	7.2	54.8	62.1	36.3
$25,000 or less	1,427	92.8	42.9	50.6	29.7
Black/White Ratio, Unadjusted			*.92*	*.74*	*.88*
Adjusted for Income			*.97*	*.77*	*.92*
By education					
Total-White	16,059	100.0	47.5	69.7	34.2
High School Grad	10,587	65.9	52.2	72.8	38.2
Less than High School	5,472	34.1	37.6	63.1	26.3
Total-Black	1,538	100.0	43.7	51.4	30.2
High School Grad	553	36.0	50.5	52.9	38.0
Less than High School	985	64.0	39.5	50.5	25.3
Black/White Ratio, Unadjusted			*.92*	*.74*	*.88*
Adjusted for Education			*.98*	*.75*	*.99*

SOURCE: Unpublished tabulations from the 1998 Medicare Current Beneficiary Survey (MCBS).

Table 2–4 shows that the total utilization rate for each service for White women exceeded the rate for Hispanic women. However, it can be observed that the rates of use of mammograms and Pap smears were greater for higher income Hispanic women than for higher income White or Black women. As Table 2–4 illustrates, when the

Hispanic-to-White ratios are adjusted for income, the ratio for mammograms increased from 0.83 to 0.91 and the ratio for Pap smears increased from 0.94 to 1.07. This illustrates the sizeable effect of differences in income distributions between White and Hispanic women. Table 2–4 also provides a comparison in utilization patterns between Hispanic and Black women. Among those with high income, the utilization rate for Hispanic women far exceeds the rate for Black women.

TABLE 2–4 Percent of Women Receiving Mammography, Flu Shots, and Pap Smears, 65 Years of Age and Over, 2000

	WOMEN		**SERVICES**		
Race or Ethnicity and Income	Number (in 1000s)	%	% with Mammogram	% with Flu Shot	% with Pap Smear
Total-White	14,240	100.0	55.0	72.9	35.6
$25,001 and over	5,033	35.3	66.0	77.2	45.8
$25,000 or less	8,500	59.7	48.0	70.5	29.1
Total-Black	1,508	100.0	51.0	55.1	38.5
$25,001 and over	150	9.9	50.8	59.7	38.1
$25,000 or less	1,296	85.9	50.1	54.9	37.1
Total-Hispanic	1,166	100.0	45.8	56.2	33.4
$25,001 and over	154	13.2	71.4	74.6	55.7
$25,000 or less	965	82.8	41.8	53.0	30.8
Hispanic/ White Ratio, Unadjusted			*.83*	*.77*	*.94*
Adjusted for Income			*.91*	*.80*	*1.07*

SOURCE: Unpublished tabulations from the 2000 Medicare Current Beneficiary Survey (MCBS) provided by Gerald Adler, Centers for Medicare and Medicaid Services (CMS).

The next two tables provide examples of two patient-based studies. Table 2–5 is from a patient-based study analyzing rates of resection of patients diagnosed with resectable non-small-cell lung cancer, by race and income. Patients were newly diagnosed during the period 1985–93. The study used the SEER/Medicare database linked to U.S. census data on a ZIP code basis.

TABLE 2–5 Rate of Resection in Early Stage Lung Cancer by Race and Median Income in ZIP Code Area of Residence

Median Income in Zip Code Area of Residence	Number of Patients		% of Patients with Lung Resection	
	Black	White	Black	White
Total	860	10,124	64.0	76.7
Lowest Quartile	451	1,907	61.9	70.7
Highest 3 Quartiles	289	6,914	67.5	78.0
Not Determined	120	1,303	63.3	78.2

SOURCE: (Bach et al., 1999).

Table 2–6 is from a patient-based study analyzing rates of different procedures following acute myocardial infarction. This study used data from the Veterans Administration. The percentage of patients with each of the procedures shown was higher for White patients than Black patients.

TABLE 2–6 Racial Variations in Cardiac Procedures Following Acute Myocardial Infarction (AMI), 1988–1990

Procedure Utilization within 90 Days of AMI	Number of Patients		% of Patients with Surgery	
	White	Black	White	Black
Total	29,119	4,522		
Cardiac Catherization	10,745	1,524	36.9	33.7
Coronary Artery Bypass Graft (CABG)	2,795	231	9.6	5.1
Percutaneous Transluminal Coronary Angioplasty (PTCA)	1,805	190	6.2	4.2
Any Revascularization	4,455	406	15.3	9.0

SOURCE: (Peterson et al., 1994).

Tables 2–2 through 2–6 illustrate the ways that household surveys, administrative databases, and patient records can be used to analyze patterns of health care for various types of services by race, ethnicity, and socioeconomic status. Clearly, these data sources have provided substantial evidence that vulnerable subpopulations receive different health care than more advantaged subpopulations. Such descriptive analyses are valuable in identifying disparities in health care and are needed to raise concerns about unequal access and utilization of health care. But the question remains: why do disparities in health care exist? The lack of knowledge about why disparities exist —even among insured populations— indicates that ongoing monitoring of health care disparities should be joined by research that focuses on analyses to understand the pathways that lead to disparities in health care and the testing of initiatives to effect a change. Table 2–7 briefly summarizes the approaches used by researchers to examine disparities.

2–4. METHODOLOGICAL ISSUES IN STUDIES OF HEALTH CARE DISPARITIES

In addition to the advantages and disadvantages of specific measures of socioeconomic status, certain other data issues must also be considered. The following presents five issues common in studies of health care disparities.

1. *Availability of data on socioeconomic status and other factors that affect disparities in health care.* Surveys that generate information about use of health care generally contain only limited information about socioeconomic status. The two measures of socioeconomic status generally collected are income and education. These measures of socioeconomic status may be useful indicators of social and economic status for some subgroups of the population, but are often relatively insensitive for other subgroups, especially for Blacks. In part, this is due to sample size. Other measures of socioeconomic status, such as wealth, would very likely be useful indicators of social and economic status. However, wealth can be extremely difficult to capture using surveys alone since people are generally unwilling to provide that information in household surveys. Moreover, recent studies indicate that lifestyle factors such as nutrition, exercise, obesity, and behavioral characteristics such as smoking cessation are also associated with disparities in health care. This suggests that the role of socioeconomic status will be difficult to disentangle from lifestyle and behavior factors especially because information about lifestyle and behaviors is generally unavailable.

2. *Using census data for measures of socioeconomic status.* Databases that lack information on socioeconomic status have been linked with U.S. census data at the census tract or ZIP code area level to assign an individual in the database the median income and educational attainment corresponding to his or her area of residence. For analytic purposes, individuals are often distributed into quartiles. If specifications for the quartiles are based on the income of the total population, then the distribution for Blacks will be uneven given the substantial differences between Blacks and Whites in income. Table 2–5 illustrates this problem. The study had a total of 10,124 White patients and 860 Black patients; 52 percent of Black patients fell into the lowest income quartile. Evidently, the three highest quartiles of patients were grouped together to overcome the problem of small cell size. Experience with this approach has shown that the problem can be avoided if income quartiles are specified separately for Blacks and for Whites. However, researchers are often limited to using databases in which certain variables, such as income, are put into a pre-specified grouping. Therefore, the "raw" data are no longer available to alter the groupings.

3. *Small cell sizes even with large samples.* Except for preventive services, utilization rates may be relatively low. Even with large databases, cell sizes may be too small to analyze rates by age, sex, race, ethnicity and socioeconomic status. Table 2–6 illustrates this problem. This study had 29,119 White patients and 4,522 Black patients. This study was published in 1994, a time when socioeconomic status had not yet been commonly used in studying disparities in health care. Had socioeconomic status been included in this study, sample size would have been sufficient. But had the data also been presented by age and sex, cell sizes for Black patients would have been too small.

TABLE 2–7 Overview of Three Approaches Used in Studying Disparities in Health Care

Advantages	Disadvantages
Surveys such as the Medical Expenditure Panel Survey (MEPS) and the Medicare Current Beneficiary Survey (MCBS)	
• Excellent source for data on race, ethnicity, and socioeconomic status. • Information nationally representative. • Contains measures of potential access such as insurance coverage and usual source of care. • Contains information about services not covered by insurance. • Contains information about health status and outcomes. • Contains information about different access and satisfaction variables. • Contains information about out-of-pocket costs.	• Limited source of data about health care services that have relatively low rates of use. • Reporting errors and non-responses may bias information. • Certain racial and ethnic groups may have small cell sizes.
Administrative databases drawn from the Medicare and Medicaid programs, the Veterans Administration (VA), and hospital discharge records	
• Excellent source for data about health care services that have relatively low rates of use. • Personal identifiers may be available to permit linkages with other data sources such as Surveillance, Epidemiology, and End Results (SEER) files. • Personal identifiers permit linkages across different types of services and over time.	• Information about services not covered and populations not available. • Information about utilization of services for enrollees in managed care plans may be unavailable. • Limited data on race, ethnicity, and socioeconomic status.

Advantages	Disadvantages
• Information on residence permits linkages with U.S. census data.	• Missing claims data or coding changes and errors create inaccuracies. • Limited clinical/patient information to assess need for services. • Medicaid programs differ across states; eligibility may be terminated. • Hospital discharge databases may not have personal identifiers for data linkages.
Clinical data such as medical records and disease registries	
• Excellent source for patient studies to analyze utilization, process, and outcomes for patients with similar needs. • SEER linked to Medicare administrative data. Excellent source of access, utilization, and outcomes data for patients diagnosed with cancer: contains date of diagnosis, site of cancer and stage of cancer at time of diagnosis. Fairly nationally representative.	• Cell sizes may be too small for various analyses. • Certain racial and ethnic groups may have cell sizes too small for analyses. • Information may not be nationally representative. • Represents patient population; therefore, is not necessarily representative of population at risk of needing services. • SEER/Medicare data source limited to persons enrolled in Medicare.

4. *Differences by race and ethnicity in risk factors.* Linking health to health care requires that differences in risk factors be recognized. To make a creditable case that disparities exist in health care, reference needs to be made to differences in risk factors. For example, the rate of amputations of all or part of the lower limb for Black Medicare beneficiaries is substantially higher than the rate for White beneficiaries. In this example, it is important to show that among elderly Blacks, diabetes (frequently the underlying cause of limb amputations) was 1.7 times the rate for elderly Whites. However, as shown in Table 2–2, the amputation rate in 1993 for Blacks was 3.64 times the rate for Whites, far greater than expected based on the difference in diabetes rates (Gornick et al., 1996).

5. *Data for persons in managed care plans.* Data are generally not available to study the effects of race and socioeconomic status on utilization in managed care plans. Policy papers have discussed the inadequacy of current information from health plans to assess disparities by race and socioeconomic status.

2–5. CONCLUSION

Incorporating knowledge from the social sciences about methods for studying socioeconomic status will help to put the NHDR on a sounder scientific footing and expand the perspective of its audiences. The examples in this paper illustrate the insights that can be gained about racial and ethnic disparities in health care when measures of socioeconomic status are included. Disparities in health care between Blacks and Whites and between Hispanics and Whites were generally reduced even with adjustment by a single measure of socioeconomic status such as income. It is important to recognize that examples in this paper show that substantial disparities in health care also occur within the White population. As income or education increased among Whites, the gradient effect was notable in several instances: the use of preventive and diagnostic services increased while the use of procedures associated with poor outcomes of care (such as lower limb amputation) decreased as income increased.

Research has shown that there are a myriad number of social and economic factors that can influence health and health care. It follows that future analyses of disparities in health care that are better able to measure and adjust for socioeconomic differences are likely to reduce racial and ethnic disparities even further. The major lesson learned from this review of research is that knowledge about disparities in health care increases when we are able to disentangle the separate effects of race, ethnicity, and socioeconomic status. In the example showing White, Black, and Hispanic rates of mammography, flu shots, and Pap smears by income groups, the rates for Hispanic women in the higher income groups differed substantially not only from White women but from Black women as well. Thus, studies of disparities in health care that aggregate data for all minority persons and present an overall measure of access and utilization are likely to obscure the fact that barriers to health care can differ for population subgroups.

The NHDR provides a major opportunity to focus attention on disparities in health care in the U.S., especially in the use of preventive and health promotion services. The vast amount of information available in U.S. data systems—as well as the experience gained in analyzing data collected in household surveys, administrative data, and medical records—can serve as a foundation for the NHDR. The challenge is to provide useful information on whether or not the health care received by vulnerable subgroups continues to differ from the health care received by persons who are more economically and socially advantaged.

Disparities in health care are likely to be more meaningful to Congress and the nation if the NHDR provides information that indicates disparities matter in terms of health outcomes. For example, rates of colonoscopy and sigmoidoscopy for Black Medicare beneficiaries have been consistently lower than rates for White beneficiaries. These differences are more likely to capture the attention of policy experts, the health care community, and the nation if they are juxtaposed against information showing that Black persons aged 65 or older have more advanced stages of cancer at the time of diagnosis and higher colon cancer death rates than White persons their age.

By depicting the types of disparities that occur in health care by race, ethnicity, and social status, the NHDR can serve a vital function not only in reporting disparities in health care, but in stimulating questions about why disparities exist. Thus, the report can serve as a foundation for conceptualizing a framework for testing hypotheses about pathways that lead to disparities in health and health care and ways of effecting a change.

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3

MEASURING DISPARITIES IN HEALTH CARE QUALITY AND SERVICE UTILIZATION

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Over the past century the United States has experienced a large decline in mortality and enjoyed significant gains in life expectancy. Yet, while the U.S. has experienced a sustained pattern of improving health status indicators, disparities in health status among American racial and ethnic minority groups have persisted. Most notably, African Americans consistently have the worst health profile among all major American racial and ethnic groups. As Williams and Rucker (Williams and Rucker, 2000) demonstrate, the overall African American mortality rate was sixty percent higher than that of Whites in 1995. This is precisely what it was in 1950.

While the pattern of racial and ethnic disparities in health has been well documented and reported, consensual explanations for racial and ethnic health disparities have been elusive. This is because much of the published research on racial disparities has focused on descriptions rather than on explanations (LaVeist, 2000). In the main, those who have attempted to explain the etiology of health disparities have provided generalized accounts. There is evidence to support environmental (Bullard, 1983; Robinson, 1989), social (Lillie-Blanton et al., 1996; Ren et al., 1999), and behavioral factors (Lannin et al., 1998), as well as factors related to socioeconomic status (Williams and Collins, 1995). However, evidence of the contribution of biogenetic factors is limited and controversial (Bach et al., 2002; Goodman, 2000; Wood, 2001). Health care is an additional area that has received attention as a possible contributor to health status disparities.

A large and growing literature has documented racial and ethnic disparities in access, utilization, and quality of care (Geiger, 2002; Kressin and Peterson, 2001; Mayberry et al., 2000). Based in part on these persistent findings, the U.S. Congress in 1999 mandated that the Agency for Healthcare Research and Quality (AHRQ) produce an annual report on the status of health care disparities, which will be called the National Healthcare Disparities Report (NHDR). AHRQ commissioned the Institute of Medicine (IOM) for guidance in designing the report.

This paper comments on various aspects of the NHDR. Specifically, this paper will:

- Identify major areas in health care services and quality where racial and ethnic disparities exist;
- Identify major areas in health care services and quality where racial and ethnic disparities are minimal;
- Identify the kinds of disparities on which the NHDR should focus; and
- Comment on approaches to reporting health care disparities.

3–1. RACE, ETHNICITY, AND DIFFERENCES IN HEALTH CARE

The relationship between patient race or ethnicity and health care services can be placed on a continuum. On one end of the continuum is health care equality, which can be characterized as health care services in which the rates of utilization for racial or ethnic minorities are equal to the rates for comparable White populations. In the middle are health care disparities, or differences in the rates of utilization of health care services where racial or ethnic minorities have substantively lower rates of utilization. On the other end are what will be called hyperdisparities, which can be characterized as greater rates of minority utilization of services that are often less desirable or a suboptimal pattern of patient service utilization that extends to access to care. Examples include greater rates of medical errors or limb amputations for diabetes patients (IOM, 2002). Other examples of hyperdisparities are ambulatory care-sensitive hospitalizations (Culler et al., 1998), missed diagnoses (Pope et al., 2000), and iatrogenic injury (Brennan et al., 1991a; Brennan et al., 1991b).

Equalities in Health Care Services and Quality

There is a generally acknowledged bias against the publication of studies that yield “nonfindings.” As such, the identification of areas without racial and ethnic disparities is more difficult than finding areas where disparities exist. While federal reports are somewhat helpful in identifying health care equalities, federal data sources in health care (as opposed to health status) are less so. Because of this, it is important to note that focusing on the number of identified health care disparities and hyperdisparities relative to the number of equalities may distort one’s perception of racial and ethnic differences in health care. However, it is possible to identify several areas of health care equality even though they are more difficult to find.

Perez-Stable et al. (Perez-Stable et al., 1995) conducted a telephone survey of Hispanic and White adults, aged 35 to 74 and living in the San Francisco area, to determine their utilization of cancer screening tests. The survey found no differences in the use of fecal occult blood tests, sigmoidoscopy, Pap smears, clinical breast examinations, and screening mammograms. Additionally, Stafford et al. (Stafford et al., 1998) examined utilization of hormone replacement therapy among African American and White patients in the National Ambulatory Medical Care Survey for 1989 and 1996. This analysis found that racial disparities in hormone replacement therapy diminished over time, particularly for women without menopausal symptoms. However, while the disparity has diminished, there are still significant differences. The adjusted odds ratio for hormone replacement in women without menopausal symptoms increased from 0.31 to 0.57, and the adjusted odds ratio among women with menopausal symptoms increased from 0.31 to 0.86.

Studies that examine a broad array of health conditions are an additional source of “non-findings.” One study examined racial differences in medical or surgical procedures in the Medicare population (Escarce et al., 1993). Of the 32 procedures examined, two (prostatectomy and barium enema) had no significant racial differences. Lee et al. (Lee et al., 1998) also studied Medicare records, but examined only 18 procedures. Eleven of the 18 procedures were not associated with disparities (coronary angioplasty, magnetic resonance imaging (MRI) of the brain, flexible sigmoidoscopy, colonoscopy, barium enema, total hip replacement, hip repair, mammogram, mastectomy, and radiation therapy).

Bennett et al. (Bennett et al., 1995) found no significant differences among African American, Hispanic, and White patients in the Veterans Administration (VA) for in-hospital mortality rates, timing of a bronchoscopy, and receipt of timely anti-pneumoniacystis carinii pneumonia (PCP) medications among HIV/AIDS patients. Findings such as these in the VA system suggest an interesting paradox. Studies of the health care system used by active military personnel have found no racial and ethnic disparities in care (Dominitz et al., 1998; Taylor et al., 1997). However, some studies of the VA system, which is used by former military personnel, have documented racial disparities (Peterson et al., 1994; Whittle et al., 1993). One plausible explanation for this is that the active duty health care system, including health care providers and patients, is part of a broad military culture tightly controlled by a chain of command that frowns on race-based distinctions. By contrast, the VA system is less closely associated with the active military. As such, its providers (and patients) are civilians. Therefore, they are influenced by social and cultural factors similar to other health care settings. Further exploration of racial disparities in the VA system compared with the active military system may be fruitful in understanding the etiology of racial disparities in health care.

Disparities in Health Care Services and Quality

Racial and ethnic differences in access and utilization of health services comprise the largest category of studies of disparities in health care. After controlling for numerous individual factors, Shi (Shi, 1999) showed that minority populations were 1.46 times more likely to identify their usual source of care as a facility rather than a person. In addition, minorities in general and Hispanics in particular were less likely than Whites to indicate that their usual care providers listened to them. Cornelius and Collins (Cornelius and Collins, 2000) found substantial differences by race and ethnicity in health insurance status and having a usual source of care. Blendon et al. (Blendon et al., 1989) found racial differences in access to care across all income groups and demonstrated severe underuse of services among African Americans.

If racial and ethnic disparities in health status are to be eliminated, access and availability of health care are major considerations. These issues are largely related to differences in socioeconomic status among racial and ethnic groups and the continuation of public policies that link health insurance to employment or citizenship. However, the problem of racial and ethnic disparities in health care extends beyond access to health care facilities. It also includes disparities in the availability of health care resources in the facilities where racial and ethnic minorities receive care. As indicated in *Unequal Treatment* (IOM, 2002), there is a large literature demonstrating racial and ethnic disparities in access to specific medical procedures after patients have entered the health care system. This literature is a diverse amalgam of studies documenting disparities in primary care (Moore et al., 1994), specialty care (McAlpine and Mechanic, 2000), surgical procedures (Escarce et al., 1993; Lee et al., 1998; McBean and Gornick, 1994), and inpatient education (Cowie and Harris, 1997).

In 2000 Mayberry and associates published a comprehensive review of the literature on racial disparities in health care, focusing on studies published between 1985 and 1999 (Mayberry et al., 2000). The article summarized a large number of studies documenting disparities across a wide variety of health conditions. Disparities were documented in health services for heart disease, stroke, cancer, diabetes, HIV/AIDS, prenatal care, immunizations, asthma, and mental health services. The conditions studied by Mayberry et al. conform to the major health conditions examined in the *Report of the Secretary's Taskforce on Black and Minority Health* (DHHS, 1985). Others have reviewed the literature as it relates to specific conditions and procedures. For example, Horner et al. (Horner et al., 1995) reviewed the literature on race disparities in health care for stroke patients, and Sheifer et al. (Sheifer et al., 2000) examined studies of racial disparities in access to coronary angiography. And still others conducted studies of disparities across numerous procedures to test for those that demonstrated major disparities compared to those that did not (Escarce et al., 1993; Lee et al., 1998; McBean and Gornick, 1994).

To identify documented areas in health care with the greatest and least health disparities, each of these types of reviews was examined. The results of this examination of the literature are summarized in Table 3–1. Table 3–1 reports selected studies of areas of health care with the largest and best-documented disparities.[1]

The best-documented disparities in health care may be those that relate to procedures for cardiovascular disease. Coronary angiography is a procedure of particular importance. Heart disease is the leading cause of death in the United States, and coronary angiography is essentially a prerequisite for percutaneous transluminal coronary angioplasty (PTCA) or coronary bypass surgery. Perhaps most striking is the finding of racial disparities in the use of coronary angiography within the VA (Peterson et al., 1994; Sedlis et al., 1997). This is because access to care is similar for all, and there is no economic incentive for either the patient or the provider related to care.

Cancer is also a condition with a large number of documented disparities in the quality of care. For example, Burns et al. (Burns et al., 1996) found that African American women were less likely than White women to receive mammography even after adjusting for use of primary care. Cooper et al. (Cooper et al., 1996) found that a higher proportion of White colorectal cancer patients (78 percent) underwent surgical resection than their African American counterparts (68 percent). Earle et al. (Earle et al., 2002) found disparities in race and socioeconomic status in referral patterns for chemotherapy among lung cancer patients. And Harlan et al. (Harlan et al., 1991) found that Hispanic women were less likely to receive Pap smears than White women.

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[1] It should be noted that variability across sample populations, settings, and databases in the studies reviewed can affect overall conclusions and generalizations on racial and ethnic health care disparities.

Other procedures related to major causes of death and/or disability include diagnostic and therapeutic procedures for cerebrovascular disease (Eggers, 1995; Horner et al., 1995), renal transplantation (Epstein et al., 2000), HIV antiretroviral therapy (Moore et al., 1994), asthma (Ali and Osberg, 1997), and participation in AIDS clinical trials (Stone et al., 1997). Marsh et al. (Marsh et al., 1999) found that physicians were twice as likely to recommend hormone replacement therapy for White patients than Blacks. And Todd et al. (Todd et al., 2000) demonstrated that 43 percent of African American patients with extremity fractures at one university hospital went untreated for pain, while only 26 percent of White patients with similar fractures went untreated. A similar study by Todd et al. (Todd et al., 1993) found that White patients with broken bones were 64 percent more likely to receive pain medication than Hispanic patients with similar fractures.

Additionally, in a recently published article, Edelstein (Edelstein, 2002) documented continuing disparities in dental health care. This is consistent with national reports showing disparities in untreated caries for African Americans and Hispanics compared with Whites (Eberhart et al., 2001). Gornick's (Gornick, 2000) study of trends in racial differences in receipt of selected health care procedures among Medicare recipients showed that ten of the thirteen procedures examined exhibited increasing disparities over time. Two procedures showed decrease and one disparity remained the same.

It can be concluded from studies of racial and ethnic differences in access and utilization of health services that racial and ethnic minorities often face the prospect of seeking care in facilities with fewer resources. And, when they obtain access to similar facilities, they often receive less optimal treatment than nonminorities.

TABLE 3–1 Areas of Health Care with the Greatest Disparities in Services and Quality (Selected Studies)

CONDITION	GROUPS	REFERENCE AND DISPARITY
Heart Disease	African American vs. White	*Ayanian et al. (1993)*—Black patients with myocardial infarction were less likely than Whites to receive thrombolysis: 9% vs. 17%. No racial difference in refusal rate.
	African American vs. White	*Peterson et al. (1994)*—Black patients with myocardial infarction in the VA system were less likely than White patients to receive cardiac recatheterization: 42% vs. 54%.
	Hispanic vs. White	*Ramsey et al. (1997)*—After adjustment for confounding factors, Hispanics were less likely to receive percutaneous transluminal coronary angioplasty than Whites: 13% vs. 23%.
Cancer	Hispanic vs. White	*Perez-Stable et al. (1995)*—Hispanic males were less likely to have a digital rectal exam within the past 2 years: adjusted odds ratio or AOR=0.54.
	African American vs. White	*Burns et al. (1996)*—After adjusting for income among women who had at least one primary care visit, White women (15%) were more likely than Black women (9%) to receive mammograms.
	African American vs. White	*Cooper et al. (1996)*—After adjusting for age, comorbidity, location and extent of tumor, White patients (78%) were more likely to undergo surgical resection than Black patients (68%).
Diabetes and Renal Disease	African American vs. White	*Epstein et al. (2000)*—Among renal transplant candidates, 90.1% of Blacks and 98% of Whites were referred for evaluation; 71% of Blacks vs. 86.7% of Whites were wait listed; 16.9% of Blacks vs. 52% of Whites underwent transplantation. Among inappropriate candidates, 57.8% of Whites and 38.4% of Blacks were referred for evaluation; 30.9% of Whites and 17.4% of Blacks were wait listed; 10.3% of Whites vs. 2.2% of Blacks underwent transplantation.
	African American vs. White	*Cowie and Harris (1995)*—African American diabetics were less likely than Whites to be treated with daily insulin injections and self-monitoring blood glucose (35% vs. 54%). Although more African Americans (43%) than Whites (32%) received patient education, the mean number of hours of instruction was lower for African Americans.

CONDITION	GROUPS	REFERENCE AND DISPARITY
	African American vs. White	*Wang and Javitt* (1996)—African Americans with diabetes were 30% less likely to have eye care visits than Whites.
HIV/AIDS and Infectious Diseases	African American, Hispanic, and White	*Moore et al. (1994)*—63% of Whites vs. 48% of Blacks received antiretroviral therapy (AOR=.59). 82% of Whites vs. 58% of Blacks received pneumoniacystis carinii pneumonia (PCP) prophylaxis. AOR=.27.
	Hispanic vs. White	*Mark and Paramore (1996)*—White patients were more likely than Hispanic patients to have received an influenza vaccine (51% vs. 35%), and were more likely to have been immunized for pneumococcal pneumonia (17% vs. 23%).
Prescription Drugs	African American vs. White	*Khandker and Simoni-Wastila (1998)*—Black children used 2.7 fewer prescriptions than White children. Black adults used 4.9 fewer prescriptions, and Black seniors used 6.3 fewer prescriptions.
	African American vs. White	*Segal et al. (1996)*—African American psychiatric patients were more likely to receive an antipsychotic agent than Whites. Odds ratio=1.67.
Pain Medication	African American, Hispanic, White, and Asian	*Ng et al. (1996)*—Analgesia prescribed by physicians for pain differed by race and ethnicity. Whites received 11.03 milligrams per hour of narcotics, Blacks received 12.13, Hispanics 9.53, and Asians 10.21.
	African American vs. White Hispanic vs. White	*Todd et al. (2000)*—African American patients presenting to an emergency department with a broken limb were less likely to receive pain medication than White patients (57% vs. 74%). *Todd et al. (1993)*—Hispanic patients presenting to an emergency department with a broken limb were less likely to receive pain medication than White patients. AOR=7.36.

SOURCE: (Ayanian et al., 1993; Burns et al., 1996; Cooper et al., 1995; Cowie and Harris, 1997; Epstein et al., 2000, Khandker and Simoni-Wastila, 1998; Mark and Paramore, 1996; Moore et al., 1994; Ng et al., 1996, Perez-Stable et al., 1999, Peterson et al., 1994; Ramsey et al., 1997; Segal et al., 1996; Todd et al., 2000; Todd et al.., 1993; Wang and Javitt, 1996.)

Hyperdisparities in Health Care Services and Quality

In an update of a 1996 study, Gornick (Gornick, 2000) examined trends in racial differences in the use of health services by Medicare beneficiaries during the 1990s. Gornick (Gornick, 2000) demonstrated three hyperdisparities: amputation of the lower limb, arteriovenostomy, and excisional debridement. One set of analyses (see Table 3–2 for information on some analyses) found that, in each case, the disparities actually *increased* between 1986 and 1994. McBean and Gornick (McBean and Gornick, 1994) found that bilateral orchiectomy was also more commonly used in African American patients. The ratio of Blacks to Whites was 1.57 in 1986 and 2.47 in 1992.

TABLE 3–2 Hyperdisparities among Medicare Enrollees Age 65 and Over

PROCEDURE	**BLACK/ WHITE RATIO OF RATES: 1986**	**BLACK/ WHITE RATIO OF RATES: 1994**	**1994–1986 HYPERDISPARITY DIFFERENCE**
Amputation of Lower Limb	3.24	3.47	.23
Arteriovenostomy	4.02	4.53	.51
Excisional Debridement	2.36	2.51	.15

SOURCE: (Gornick, 2000).

Culler et al. (Culler et al., 1998) examined Medicare administrative records to identify patient characteristics associated with potentially preventable hospitalizations and found that African American patients were more likely to have such hospitalizations. Brennan et al. (Brennan et al., 1991a; Brennan et al., 1991b) found that hospitals that serve primarily minority patients have similar rates of adverse events compared to those hospitals that do not treat predominantly minority populations. Yet these same hospitals have significantly higher rates of adverse events due to medical negligence or errors compared to those hospitals not treating predominantly minority patients. Even after controlling for hospital characteristics and for disease severity and complexity, the only factor that remains consistently associated with an increased risk of adverse events due to negligence is a large proportion of discharged minority patients.

3–2. CREATING A NATIONAL HEALTHCARE DISPARITIES REPORT

There are numerous factors to consider in determining the types of disparities that should be the focus of the NHDR. Since the report will need to rely on existing data sources (at least in the short term), this presents a set of limitations that may hinder the utility of the report. Many existing data sources can be used to adequately measure morbidity, mortality, and health risks such as smoking and obesity. However, there are fewer national databases that can be used to measure health care indicators. The Centers for Medicare and Medicaid Services (CMS) offer a good source of data on health care disparities among the elderly. Similarly, the Medical Expenditure Panel Survey (MEPS), the Healthcare Cost and Utilization Project (HCUP), and the National CAHPS (Consumer Assessment of Health Plans) Benchmarking Database (NCBD) are all potential sources of data, at least in the short term. But sources of national data on disparities in underuse or overuse of specific medical procedures for non-Medicare or Medicaid populations are still more limited.

In establishing criteria for the selection of measures for the NHDR, there are a variety of factors to consider. One might select procedures with the highest costs or those that are the most thoroughly documented. One might also select procedures associated with conditions with the highest mortality rates or the greatest number of years of potential life lost. However, these approaches are somewhat problematic. Years of potential life lost would tend to select causes of death for younger Americans such as nonchronic conditions and homicides, accidents, and injuries. These are important, but tertiary considerations. Rather, a conceptual framework should be used that combines the continuum of health care disparities (equalities, disparities, and hyperdisparities) with the four consumer perspectives on health care needs, as discussed in *Envisioning the National Healthcare Quality Report* (IOM, 2001). The continuum of disparities would range from equality, or the absence of disparities; to disparities, or less evidence-based care for racial and ethnic minorities than that provided for majorities; to hyperdisparities, or care disproportionately provided to racial and ethnic minorities that can indicate lack of care or poor prior care. The consumer perspectives on health care needs are staying healthy, getting better, living with illness or disability, and coping with the end of life. By combining the continuum of disparities with consumer perspectives on needs, one can create a matrix as displayed in Table 3–3. By employing this framework, one can produce a set of candidate measures that fit into each cell of the matrix. Once the set of candidate measures is completed, then secondary considerations can be employed to select a set of measures for the report.

TABLE 3–3 Assessment of Measures for Health Care Disparities

	CONTINUUM OF DISPARITIES		
CONSUMER PERSPECTIVES ON HEALTH CARE NEEDS	**HEALTH CARE EQUALITIES**	**HEALTH CARE DISPARITIES**	**HEALTH CARE HYPER-DISPARITIES**
Staying Healthy			
Getting Better			
Living with Illness			
Coping with the End of Life			

The following are recommended secondary considerations:

- Indicators are applicable to multiple racial and ethnic groups. The indicators must be applicable to all racial and ethnic groups that make up the U.S. population.
- Data sources must be accessible. The report card must be easily understandable to a broad population of health care consumers, and the indicators must have high “face validity.”
- Indicators are not confounded. Indicators must not be confounded with other variables such as health insurance, patient preferences,

or larger societal factors. Or, if there is confounding, there must be ways to adjust for it.

Indicators are longitudal. The indicators must have the ability to be replicated over time.

Data Sources

A review of the literature suggests that there are three types of data that show at least some promise: patient assessments; medical/administrative record data audits; and health outcomes. They are described below.

Patient Assessments

There are numerous examinations of patient satisfaction and health-related quality of life that can be incorporated into quality assessments (Cleary and Edgman-Levitan, 1997). Lewis (Lewis, 1994) has provided a comprehensive review of this literature. Such assessments are typically based on patient surveys. A variety of measures of quality, satisfaction, and quality of life has been validated. Patients' assessments of quality of care can be aggregated to produce scores that can be assessed within and between racial and ethnic groups. Cleary and Edgman-Levitan (Cleary and Edgman-Levitan, 1997) suggest that such measures would go beyond satisfaction and include measures designed to assess respectful treatment of patients and involvement of patients in treatment decisions. These are consistent with the concept of patient centeredness. CAHPS and potentially MEPS are examples of patient assessment data sources.

Medical/Administrative Record Data Audits

There is a large literature demonstrating racial differences in the medical and surgical management of conditions within health care settings. After controlling for access to care, studies have found that a patient's race predicts treatment decision making across a variety of conditions including breast cancer (Burns et al., 1996), prostate cancer (Klabunde et al., 1998), bladder cancer (Mayer and McWhorter, 1989), glaucoma (Javitt et al., 1991), and psychiatric conditions (Chung et al., 1995).

Health Status Outcomes

A growing body of health care quality data suggests that iatrogenic injury should be considered an important component of the total quality of care picture. The literature indicates that a significant proportion of adverse events are due to errors in medical judgment that result in delivered care that is lower than commonly accepted medical standards. Those events that result in significant disability, morbidity, and/or mortality to the patient are by definition said to be due to negligence (Brennan et al., 1991a; Brennan et al., 1991b). HCUP (although geographically limited) is an example of data that can be used to produce estimates of components of health care quality from hospital discharge data.

Approaches to Reporting

It is important that the data are reported in a way that is accessible to policy makers and the general public. The U.S. Department of Labor produces a set of economic indicators that is closely watched and widely regarded as a gauge of the economic status of the country (for example, the Consumer Price Index, the Employment Cost Index, the Employment Situation, the Producer Price Index, Productivity and Costs, Real Earnings, and the U.S. Import and Export Price Indexes). It is possible to create such measures for health status, health care quality, and disparities that could serve as “the health disparities index.” There is some experience with such measures in health, including the World Health Organization’s “Global Burden of Disease” project. One undesirable aspect of “global measures” is that it is inevitable that they will mask some degree of variability (Nygaard, 2000). However, such a measure would be a valuable tool in informing the public and policy makers. An advantage of global measures is that they provide a summary statistic that is reflective of the general pattern of health care disparities, thereby avoiding details that may be unnecessary for policy makers and others to consider.

The specific computation of such an index is beyond the scope of this paper. It would be valuable to invest some resources in the creation of a set of global measures of health care disparities. These measures would aid in monitoring progress in improving the nation's health in general and eliminating health care disparities specifically. Additionally, such measures would eliminate the need to establish one racial and ethnic group (typically Whites) as a standard against which other groups are compared. The race-comparative approach has several undesirable aspects (as will be described below).

The standard formats of reporting disparities used in health care research include risk ratios, odds ratios, and difference scores. Each of these methods has disadvantages. Table 3–4 presents simulated data on use of cardiac catheterization among 250 African American and White patients who were appropriate candidates for the procedure.

To calculate the risk ratio (also called the rate ratio or ratio of rates), one would compute the ratio of the percentage of patients in each group who received catheterization. Thus,

Risk Ratio=.33÷57.=.58

This statistic represents the risk of receiving catheterization for African Americans relative to Whites. However, it does not account for the possibility of overutilization of the procedure among Whites.

TABLE 3–4 Simulated Data

RECEIPT OF CARDIAC CATHETERIZATION	**PATIENT RACE: BLACK**	**PATIENT RACE: WHITE**	**TOTAL**
No. of Patients	75	175	250
No. Receiving Procedure	25	100	125
% Receiving Procedure	33%	57%	50%
Predicted % of Cardiac Catheterizations Received by Group	30%	70%	100%
Observed % of Cardiac Catheterizations Received by Group	20%	80%	100%

A second standard approach is to compute the odds ratio. This statistic is computed by taking the ratio of the odds of receiving catheterization for one group relative to the other. Thus, the odds of receiving catheterization for African Americans are 25÷50=.5 and the odds for Whites are 100÷75=1.33. The odds ratio is .5÷1.33= .38. This statistic represents the degree of disparity in the relative odds of getting catheterization. Like the risk ratio, it expresses disparity relative to Whites.

A third approach is to take the simple difference in percentages for each group. Thus, 57 percent of Whites receive a procedure compared to 33 percent of African Americans: 57`33=24.

A limitation to each of these approaches (besides again using one group as the standard) is that the magnitude of the difference is not changed by qualitative differences in the rates. For example, 25` 1= 24. Also, 100`76=24.

One approach to consider is the ratio of health care inequality. This statistic can be computed by first computing predicted and observed percentages of catheterization received by each group. This can be done as follows: determine the number of total patients that African Americans and Whites represent (75÷250=.3×100=30 percent for African Americans. For Whites, 175÷250=.7×100=70 percent). Since African Americans comprise 30 percent of the patients who need the procedure, one would expect they would receive 30 percent of the catheterizations. The degree to which the predicted percentage of catheterization deviates from the observed percentage indicates the degree of disparity in obtaining health care resources that were expended. Thus the ratio is produced by computing the ratio of observed to predicted catheterizations. For African Americans, 20÷30 =.67, and for Whites, 80÷70=1.14. It can be said, therefore, that African Americans received 67 percent of the catheterizations that they should have received, and Whites received 14 percent more than their share. This approach can be used to produce a unique score for each group, including Whites. Also, the score is easily understood. A score of 1 can be interpreted as equilibrium between observed and expected utilization. A score greater than 1 indicates that the procedure is used in the group more than one would expect given a colorblind allocation of resource.

3–3. CONCLUSION

This paper has presented issues for consideration in the development of the National Health Disparities Report. The considerations are summarized by the following suggestions. Create a framework for the categorization of health disparities that includes the continuum of health care equalities, disparities, and hyperdisparities as well as the four consumer perspectives on health care needs: staying healthy, getting better, living with illness or disability, and coping with the end of life (IOM, 2001). In addition, adopt a set of criteria to use in the selection of individual measures. Criteria suggested include applicability to multiple racial and ethnic groups; accessibility to a broad population of health care consumers; limited confounding; and replicability.

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4

MEASURING DISPARITIES IN ACCESS TO CARE

Nicole Lurie

Since the landmark *Report of the Secretary's Task Force on Black and Minority Health,* minority Americans have been consistently shown to have poorer health status and worse health outcomes than White Americans (DHHS, 1985). These differences have remained so persistent that *Healthy People 2010* specified the elimination of disparities in health as one of its two overarching goals (DHHS, 2002). Included among the health disparities of most concern are those between different racial and ethnic groups and those associated with geography. There is now an emerging consensus that disparities, at least between different racial and ethnic groups, arise from several factors. These include differences in access to care and health insurance and in the amount and quality of care offered and received. They also appear to arise from factors not directly related to the health care system such as socioeconomic status, literacy, language, community factors affecting health, and differences in access to opportunity (Williams, 1999).

The national goal of eliminating health disparities has led to a reexamination of the health care system and a call for intensive measures to move the nation well along toward meeting the goal (National Archives and Records Administration (NARA), 1997). Learning from the quality movement, there has been heightened awareness that measurement is key to achieving success. Hence, in its reauthorization in 1999, the Agency for Healthcare Research and Quality (AHRQ) was directed to prepare a National Healthcare Disparities Report (NHDR), and it has formed an Office of Priority Populations (AHRQ, 1999). These events coincide with a closely related effort: the development and publication of the *National Healthcare Quality Report* (IOM, 2001c). An earlier report from the Institute of Medicine (IOM), *Crossing the Quality Chasm,* draws attention to the intimate relationship between quality and disparities by its position that equity is one of the key aspects of quality (IOM, 2001b).

In preparation for the NHDR, AHRQ has commissioned the IOM to create a committee to provide guidance on how to address various topics, including access to care. This paper is intended to provide background and fresh thinking for the Committee for Guidance in Designing a National Healthcare Disparities Report on the leading issues surrounding the measurement of disparities in access to care.

4–1. SETTING THE CONTEXT

In a seminal article that provides a conceptual framework for access to care, Aday and Andersen identify a combination of policy variables such as the presence of health insurance, personal variables (predisposing, enabling, and need), and process of care elements (for example, use) that lead to an outcome (Aday and Andersen, 1974). Since the article's publication over a quarter century ago, much has sadly remained the same such as the lack of health insurance and primary care. But much has also changed, and the challenge of measuring disparities in access to care in the early 21st century must account for these new realities.

Several are highlighted here:

- National demographics are shifting dramatically, and the U.S. is much more multi-ethnic than at any time in its history. Some states, such as California, are already "majority minority states," and the proportion of the population that is Hispanic is expected to grow dramatically in the next decade (U.S. Bureau of the Census, 1996). Although African Americans as a group continue to have some of the worst health outcomes, discussion of health disparities for racial and ethnic minorities must move well beyond comparisons of African Americans and Whites.

- Concurrently, there has been a shift of the population from rural to urban and suburban areas (U.S. Bureau of the Census, 2002a). Populations in rural areas have declined and aged as younger people have moved to more urban environments. The recent influx of immigrant populations, who often work on farms and in meat processing plants, has changed the ethnic composition of rural areas as well.
- The aging of the population and a longer life expectancy mean that chronic disease is now much more prevalent. Concomitantly, our understanding of how best to care for people with chronic disease is improving. Attention to end-of-life care has provided new opportunities for people to receive care at home, and the dying process has become more patient centered. At the other end of the age continuum, survival among severely impaired infants has increased, and these children often require continuous personalized medical care services.
- There have been major and continued shifts in the financing and organization of care. While most insured Americans are enrolled in some form of managed care, the heterogeneity among health plans means that it is harder to generalize about them. Nonetheless, some common elements have facilitated our ability to examine and address disparities. Explicit attention to responsibilities for enrollees (or identification of a denominator population) creates important opportunities to measure both access and quality within health plans. With this has come increased accountability, a key element of which is measuring and reporting. Managed care has also reintroduced the concept of population health. Once considered analogous to public health, it is now well recognized that caring for populations is effectively done both *inside* the personal health care system and *outside* of it. Managed care has also brought with it pressure to reduce health care expenditures and concerns that access and quality could be compromised.
- Uninsurance—and underinsurance—remain major problems for over 60 million Americans, and there is no foreseen decline on the horizon (Commonwealth Fund, 2000). The amount that

individuals must pay for care is increasing, and half of all seniors report needing to cut back on essentials such as food and heat in order to pay for medications (Families USA, 2001). The array of payment arrangements, deductibles, co-payments, and benefits has grown dramatically. Nonetheless, the uninsured, minorities, low-income populations, and rural residents disproportionately receive care in a separate, unmanaged system composed of community health centers, nonprofit clinics, various charity care arrangements, and emergency departments (IOM, 2000).

- Our understanding of what causes disease is becoming clearer. Specifically, it is now estimated that up to 50 percent of health status can be accounted for by health behaviors and only 15 to 20 percent by the health care delivery system (McGinnis et al., 2002). In other words, health care system factors contribute proportionately less to health status when compared to other factors, although the benefits are greatest for those in poor health and without access to care. Importantly, advances in genetics have confirmed that race is not a biologic construct, but a social one. There is more genetic variation within racial groups than between them (President’s Commission, 1983).
- Our understanding of health has broadened. Specifically, mental health and oral health have been more clearly defined as important components of health, and concepts like well-being or spirituality are increasingly thought to be integral to health.

While the environment in which health services are provided has changed, the view of access to care has largely remained the same.

4–2. EVOLVING CONCEPTUAL FRAMEWORKS OF ACCESS TO CARE

Our understanding of access to care has evolved over the last 25 years. The conceptual framework developed by Aday and Andersen identified the relationships among personal characteristics, policy variables, utilization, and outcomes. As the framework evolved, “potential access” became defined by characteristics of the delivery system and of individuals in the area. These were further divided into the now familiar predisposing, enabling, and need variables, measured at both the individual and community levels. "Realized access" was represented by utilization. It was also represented by experiences with care and equity of access that required that the distribution of services be based on need (Andersen and Aday, 1978; Andersen et al., 1983).

The 1983 President's Commission for the Study of Ethical Problems in Medicine and Biomedicine and Behavioral Science Research further emphasized the issue of equity in access in declaring that "equitable access to health care requires that all citizens be able to secure *an adequate level* of care without excessive burdens"[1] (President's Commission, 1983, p. 4). While it did identify a standard of "equity," it did not define "adequate level of care" or how it might contribute to outcomes.

The IOM revisited the issue of access to care in 1993, defining access as "the timely use of personal health services *to achieve the best possible health outcomes"*[2] (IOM, 1993). Of note, in choosing indicators that represented access-related outcome measures, it more explicitly linked access to quality and implied that everyone should have access to care to make these "best possible" outcomes achievable. The committee recommended a series of indicators that affect outcome measures through the processes of entering and staying in the health care system, the utilization of services, and quality of care. The report depicts a more linear relationship between access and outcomes starting with structural, financial, and personal barriers and moving through the use of services and "mediators" (which are largely measures of quality) to outcomes. It acknowledged the complexity of identifying access issues, but did not address the extent to which a poor performance on outcome measures is a direct function of poor quality of care or of barriers to access before or after an individual has entered the delivery system.

The advent of managed care brought with it a set of additional factors that relate to access. This expanded framework is embodied in the work of Docteur et al., who identify a complex series of factors

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[1] Emphasis added.

[2] Emphasis added.

related to access and quality in managed care (Docteur et al., 1996). The authors include a number of contextual community variables such as available plan choices, active marketing and market characteristics, and stability of plan choices. They also recognize that access today may require navigating managed care plans, for example, to obtain referrals for care or to appeal denials. It is not clear how this challenge differs substantially from navigating the health care system as a whole.

Finally, *Envisioning the National Health Care Quality Report,* issued by the IOM's Committee on the National Quality Report on Health Care Delivery, articulated a framework for consideration of quality, which is not unrelated to the frameworks described above (IOM, 2001c). It takes the form of a matrix in which the rows describe consumer perspectives on health care needs (staying healthy, getting better, living with illness or disability, and coping with the end of life) and the columns describe components of health care quality (safety, effectiveness, patient centeredness, and timeliness). The relationships between access to care and this framework are important and are described in detail below.

Neither the frameworks for describing access nor that for the *National Healthcare Quality Report* yet incorporate our knowledge of what creates health or evolution in the health care system. The Docteur et al. framework is something of an exception: it identifies community contextual variables (such as market competition) and available plan choices as access-related issues.[3] However, as our understanding of factors that create health develops, it is clear that the nature of communities themselves and access to a well-functioning public health system are critical to achieving access to personal services. Increasingly, place appears to have an effect that is independent of socioeconomic status (Davey-Smith et al., 1998). Consider, for example, factors that influence access to HIV care. A community's socioeconomic status and its physical and social environment affect the probability that one will become infected with HIV. Twenty-five percent of infected individuals in the U.S. do not even know they are infected and are thus completely unaware of the need for care (CDC,

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[3] Andersen and Aday (Andersen and Aday, 1978) identify demographic characteristics of individuals in communities, such as the percent over age 65 or in poverty, as having potential impacts on access.

2002). Late presentation of disease is a major determinant of bad outcomes in this disease, which disproportionately affects minority populations. While some of these individuals may have had missed opportunities for HIV detection in the personal health care system (a quality issue), the nature of the community and the failure of public health efforts to maximize knowledge of HIV serostatus are major barriers to access. Late stage presentation of other diseases, including certain cancers, diabetes, and heart disease, also provides examples of how access is tied to the effectiveness of the public health system.

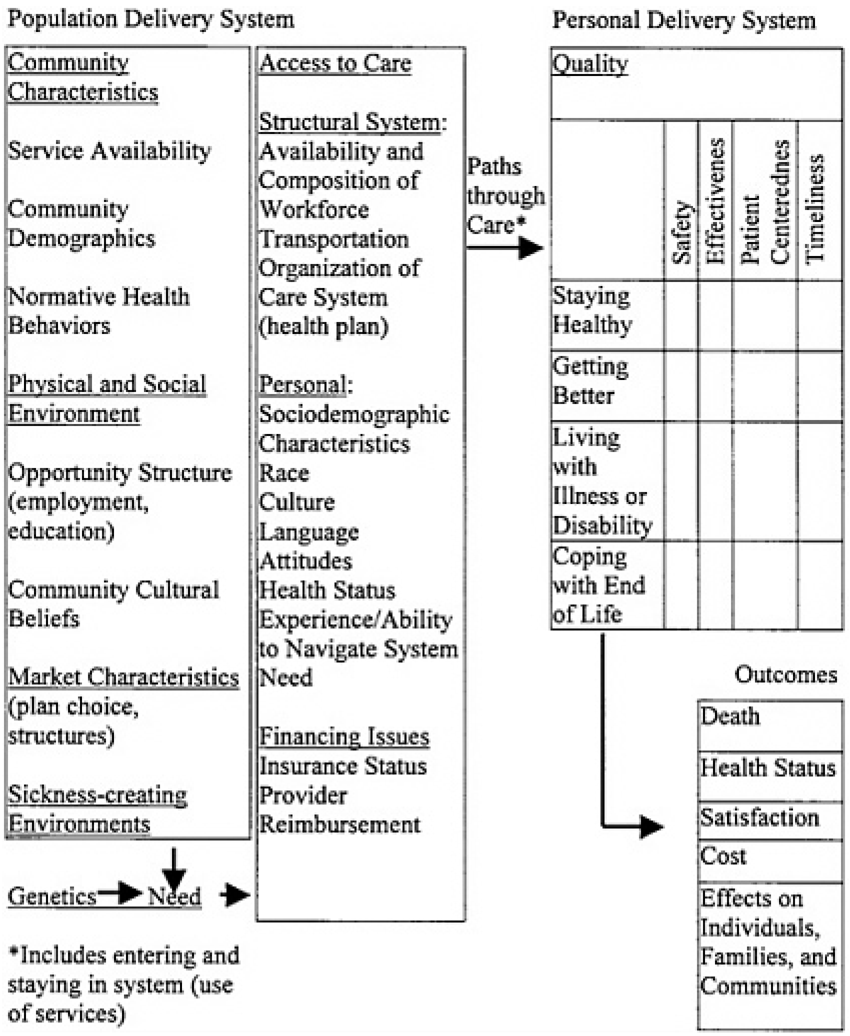
An example of the importance of a community environmental factor is oral health. It is well documented that low income and minority children have poorer oral health and less access to preventive or restorative dental services. Fluoridation is the single most effective intervention in preventing caries, but approximately one-third of the U.S. population does not have access to fluoridated water, particularly in rural areas (National Institute of Dental and Craniofacial Research, 2000).

Risk behaviors are irrefutable contributors to health outcomes, and many of these behaviors are modifiable. Changing health behavior is a joint function of the individual, the public health system (largely through increasing awareness and education), and the delivery system. Yet, the current conceptualization of access to care with regard to behavior change places the responsibility either solely with the patient or *inside* the health care system, often within the patient-provider encounter. A recent review of a campaign to promote smoking cessation during pregnancy found that the campaign did not focus on minority populations, which have the highest rates of smoking and SIDS (Lewis, 2001). Women who are unaware of the risks of smoking during pregnancy are less likely to seek or use smoking cessation services.

Finally, it is recognized that for most chronic disease, the major caregiver is the patient and/or family. Most care (for example, medication adherence, adherence to risk reduction behaviors, and self monitoring) actually occurs in the home, where the level that patients receive is largely influenced by their communities.

Hence, it is clear that the community, the public health system, the personal delivery system, and the individual all share responsibility in working to achieve optimal health outcomes. Figure 4–1 combines the frameworks discussed above to depict this relationship.

FIGURE 4–1 Relationship between Population and Personal Delivery Systems



4–3. ACCESS TO CARE AND THE QUALITY FRAMEWORK

The framework presented in *Envisioning the National Health Care Quality Report* highlights the fact that access to care can be a significant issue, even after someone has entered the health care delivery system (IOM, 2001c). Clearly, access throughout the lifespan to the full array of services identified in the rows of the framework is an important policy goal. Key aspects of access are related to each of the domains of safety, timeliness, effectiveness, and patient centeredness. Table 4–1 and Figure 4–2 identify examples of access indicators that can easily be placed in different cells of the quality framework.

The following is a discussion of the relationship of access to the framework's four components of health care quality (timeliness, safety, effectiveness, and patient centeredness) and to the four consumer perspectives on health care needs (staying healthy, getting better, living with illness or disability, and coping with the end of life).

Timeliness is unquestionably a component relevant to both for entering and staying in the system.

With regard to **safety,** several studies have suggested that poor and minority patients are more likely to experience medical errors and are more likely to have cardiac procedures performed by providers with poorer outcomes. Whether this results from patients' uninformed choice of providers, the lack of availability of other providers to care for these individuals, or other factors is unclear. However, access to safe care is critical for optimal outcomes. Access to care that is not safe may actually be worse than no care.

TABLE 4–1 Example of Access-related Quality Measures

	COMPONENTS OF HEALTH CARE QUALITY			
Consumer Perspectives on Health Care Needs	Safety	Effectiveness	Patient Centeredness	Timeliness
Staying Healthy	Safe Immunization Practices	Mammogram rate	Ability to Understand Clinician	Cancer Screening and Follow-up
	Radiation Guidelines	Pap Smear Rates	Ability to Understand Process of Managed Care	Preventive Oral Health Care
		Prenatal Care	Ability to Navigate Health Care System	
		Immunization	Availability of Language Translation Services	
		Hypertension Awareness	Composition of Workforce	
		Cholesterol Awareness	Information that Care is Needed	
Getting Better	Potentially Avoidable Adverse Events	Knee Replacement for Arthritis	Ability to Understand and Follow Treatment Plan	Time to Thombolytic Therapy for Myocardial Infarction (MI)
	Potentially Inappropriate Utilization of Procedures	Pain Control		Time to Setting Long Bone Fracture

	COMPONENTS OF HEALTH CARE QUALITY			
Consumer Perspectives on Health Care Needs	Safety	Effectiveness	Patient Centeredness	Timeliness
Living with Illness or Disability	Access to High Quality Providers	Transplant for End Stage Renal Disease Foot and Eye Exams for Diabetics	Culturally Appropriate Home Nursing	Ambulatory Care Sensitive (ACS)/ Emergency Dept. Sensitive Admissions
Coping with End of Life	Safe Nursing Homes	Effective Pain Management	Culturally Appropriate Counseling about Hospice Services	Time from Request for Hospice to Admission

With regard to **effectiveness,** we are not terribly concerned with ensuring access to care that is ineffective provided it is not harmful. However, data suggest that minority patients receive fewer effective, need-based treatments that improve health and quality of life such as knee replacements for severe arthritis or renal transplants for end stage renal disease. As is often the case, it may not be possible to disentangle access and quality because so many factors are involved. For example, insurance status is clearly related to arthritis care in general and to knee replacement rates in specific, which could lead one to conclude that knee replacement rates reflect financial access to care.

However, barriers such as a lack of physician recommendation to undergo such a procedure or a poor explanation of patient options are quality-related access barriers to receipt of such a procedure. Even when the issue of insurance is removed, as for example in Medicare's program for end stage renal disease (ESRD), factors such as a lack of discussion or recommendations about options for treating renal failure appear to account for a substantial part of the difference in transplant rates between Whites and African Americans (Ayanian et al., 1999). While an argument can be made that this is purely a quality of care issue, one cannot access treatments of which one is unaware.

A comprehensive review of this issue can be found in the IOM study, *Unequal Treatment* (IOM, 2002b). That report suggests that provider-related factors such as bias, discrimination, and stereotyping--as well as patient-related factors such as mistrust and variability in presentation of symptoms—explain much of the phenomenon of disparate access to effective care. While there are not yet good measures of many of these factors to more directly test this hypothesis, development and use of such measures should be a goal of subsequent editions of the NHDR. Regardless, it is safe to conclude that even once inside the health care system, there are numerous examples of disparate access to effective care.

Access shares key relationships with another aspect of quality, **patient centeredness,** which includes such issues as workforce demographics and cultural competence. The degree to which the demographics of the health care workforce reflect the population cared for is a significant access issue. First, minority physicians are more likely to provide care for minority patients (Komaromy et al., 1995). The race and ethnicity of the health care provider are also factors in the choice of physician for up to 40 percent of minority patients (Commonwealth Fund, 2002; Saha et al., 2000). Additional studies suggest that gender and race concordance is important in patient-doctor communication and receipt of preventive care (Cooper-Patrick et al., 1999; Docteur et al., 1996; Saha et al., 1999). Access to a diverse workforce differs from cultural competence. There is no evidence to suggest that minority physicians are more culturally competent simply by virtue of their race or ethnicity. However, a diverse provider workforce improves cultural competence by exposing all providers to peers of different racial and ethnic backgrounds. Cultural and language barriers to access have long been recognized as impediments to patient-centered access. Beyond the provision of language access and provider knowledge of cultural beliefs and traditions, there has not been general agreement about what cultural competence is. However, core components have been proposed (Brach and Fraser, 2000; California Pan-Ethnic Health Network (CPEHN), 2001).

Each of the consumer perspectives on health care needs identified by the framework for the National Healthcare Quality Report should be examined for their implications for our understanding of health and what creates it. Access-related aspects of these domains are briefly discussed below:

Staying healthy involves an array of access-related health behaviors and preventive services that occur across the lifespan, and many of these are well understood. There is, for example, a large body of work on access to breast and cervical cancer screening. In addition, appropriate follow-up after an abnormal Pap smear or mammogram is important to access, quality, and outcomes. This is an area in which large disparities are thought to exist.

Getting better refers primarily to getting acute care, and measures are discussed below.

Two aspects of the continuum of care have changed substantially since access to care was initially conceptualized: care for chronic disease and end-of-life care. **Living with chronic disease and disability** has become more common, and it is clear that aggressive management can prevent complications and declines in function. This has led to the evolution of new models for chronic disease management (Wagner et al., 2001). These often involve team-based care including, for example, nutritionists or physical therapists. If these models are demonstrated to be pathways for achieving the "best possible outcome," access to chronic disease management services will become even more important. Because minority patients are disproportionately affected by some of the conditions most amenable to disease management programs, including diabetes or asthma, access to these services should be a consideration in the NHDR. There are no large data systems that currently measure need-based access to, or use of, disease management services. However, some aspects of team-based care can be examined through medical claims.

Coping with the end of life has also become more important as the population ages. Cultural differences associated with ethnicity and geography often affect the nature of end-of-life care and are associated with differing degrees of informal caregiving. The wide variation in preferences makes measures of service utilization somewhat difficult to interpret. Nonetheless, three common measures of use of end-of-life care services—use of nursing home care, use of home nursing, and use of hospice care-are available from Medicare administrative data. With regard to geography, only 11 counties in the U.S. do not have a hospice provider serving them. This does not necessarily mean that someone in need of hospice care can get it. Recent work indicates relatively small racial and ethnic differences in use of hospice services or skilled nursing facilities (Lynn and Shugarman, 2002).

Because Medicare covers much of the population needing both chronic care and end-of-life care, access to these services does not seem to be as problematic as it is for the uninsured. However, older rural residents are less likely than the rest of the population to be covered by Medicare. Further, Medicare alone does not provide sufficient financial access for many seniors for whom the co-payments, deductibles, and drug costs all pose financial barriers to care. The availability of Medicaid coverage for low-income senior populations, which are disproportionately rural and minority, varies from state to state, again limiting access for many low-income Medicare beneficiaries. Some states with large minority and rural populations have some of the least generous Medicaid programs.

Additional factors such as geographic access; the ability to understand the clinician or to participate in informed decision making; the ability to navigate the health care system; language access and availability of translation services; and access to understandable information before, during, and after the health care encounter all affect care throughout the continuum.

This discussion has highlighted the relationships between access and quality in terms of the framework presented in *Envisioning the National Health Care Quality Report*. These relationships and their interface with community factors are depicted in Figure 4–2.

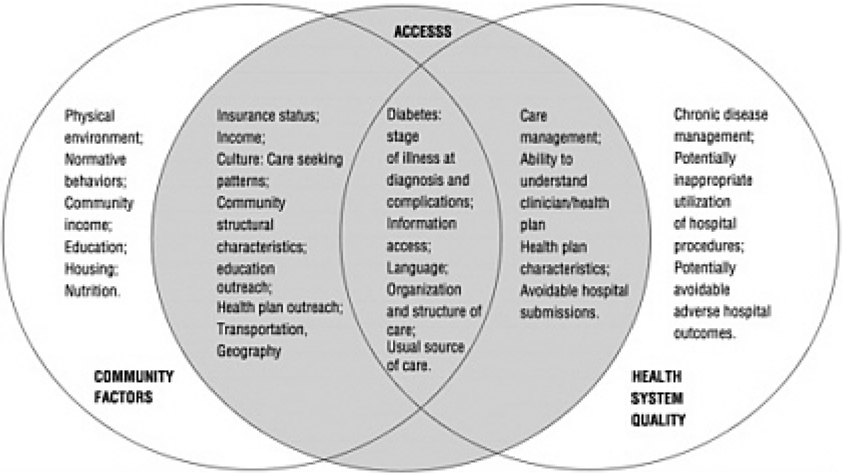
4–4. CHALLENGES TO EXAMINING DISPARITIES IN ACCESS

A series of issues challenge the examination of disparities in access in the NHDR. They include issues related to data and measurement, socioeconomic position, cumulative effects, managed care, undercounted populations, and utilization as a measure of access. The following is a brief treatment of each.

Data and Measurement

A series of data and measurement issues will be relevant to consideration of the types of measures used and their presentation. A forthcoming report from the National Center for Health Statistics (NCHS) outlines some of the methodological issues in calculating disparities such as whether the differences are relative or absolute, whether they are framed in the positive or negative, and whether a summary disparity score for a given measure is useful (Keppel, 2002; National Center for Health Statistics, 2001). Many of the decisions to be made regarding these issues will depend on the context in which they are being used.

FIGURE 4–2 Relationship among Access to Care, Community, and Health Care Quality



Another issue relates to heterogeneity of the populations studied. Each of the racial and ethnic groups and the groups of individuals considered “rural” varies tremendously by subgroup. African- and Caribbean-born Blacks clearly have different health status and health outcomes than American-born Blacks. Hispanics and Asians come from many countries, and they differ widely in the health behaviors and cultural patterns that affect access and use. There is tremendous variation in rural areas: culture, lifestyle, and health needs differ widely among, for example, rural North Dakota, Texas, and Appalachia. Aggregation by race or by urban/rural status masks many of these differences, just as examining the total population masks differences by major racial and ethnic groups.

A more complicated set of issues concerns data availability and quality. The recent census includes the numbers of individuals who self report mixed race or ethnicity, a different kind of classification issue. Continued increases in those reporting more than one race or ethnicity will make comparisons from baseline data difficult. The Office of Management and Budget (OMB) is developing a crosswalk that will facilitate examination of changes over time.

Racial misclassification continues to be an issue of concern in many data sources (IOM, 2002b). This is most likely to occur when an individual’s race is not obtained by self report, but rather through observation by a third party such as a clerk assessing eligibility. While most of the large national survey efforts obtain self-reported information about respondent race and ethnicity, these data are not routinely collected and recorded in most health care databases, which are often sources of information regarding utilization of care.

Race and ethnicity data are sometimes available by linking administrative and utilization data, and these vary in accuracy by data type (for example, Medicare and Social Security, Medicaid and eligibility files, and race and ethnicity). In addition, race and ethnicity data are available from hospital discharge data in states contributing to the Hospital Cost and Utilization Project (HCUP), although the amount of missing data is often substantial. Most health insurers and health plans do not routinely record this information, making it extremely difficult to measure utilization or quality for different racial and ethnic subgroups. A recent review of all state laws regarding the collection of racial and ethnic data by health plans highlights the possibilities of collecting race and ethnicity data in all states, although laws in a few states preclude its collection prior to health plan enrollment (Youdelman, 2001). Efforts to encourage collection and use of racial and ethnic data are underway in both the public and private sectors. This suggests that it should be possible to use this information for future measures of access and quality. Currently, Medicare data provide the greatest opportunity to measure disparities in use of services.

Availability of data is not necessarily sufficient to answer important questions. In many epidemiological databases and national access and utilization surveys, minority subgroups are too small to make comparisons between groups possible. This is especially true for information at the state or health plan level. This problem becomes even more acute for measures drawn from sources such as the Health Plan Employer Data and Information Set (HEDIS) or the Consumer Assessment of Health Plans (CAHPS) in individual health plans, particularly within given diagnoses. Recent attempts to examine such data for Medicare+Choice health plans found no plans with at least 30 enrollees in each of the major race and ethnicity classifications and less than a dozen plans in which there were sufficient numbers of Asian Americans or Hispanics to analyze. While there were many plans that had at least 30 African American and White enrollees, sample sizes that small make even simple comparisons very difficult (Lurie et al., 2002).

Socioeconomic Position

Some conceptual and philosophical challenges underlie interpretation of racial, ethnic, and geographic differences. Foremost among them is the consideration of socioeconomic status and how it relates to racial, ethnic, or geographic disparities. A long literature has attempted to disentangle these relationships, finding that if socioeconomic status is “controlled for,” the magnitude of the disparity attributed to race or geography becomes smaller. However, such analyses are often used to dismiss the fact that serious disparities exist. Moreover, they do little to illustrate how race affects socioeconomic position or opportunity or to disentangle the separate effects of education and income (Williams, 1999).

Furthermore, if we accept that community-level socioeconomic factors affect access or are etiologic in creating need, they need to be considered in measuring access, especially since addressing them may lead to improved outcomes. Some of these include conditions associated with poverty, such as poor access to quality schools, poor housing, undernutrition, and substance abuse. Each of these conditions contributes to poor health. They act to impede access in ways that go beyond the contributions of factors such as cost or transportation. In addition, they change the nature of perceived needs and the internal resources for addressing them. The immediate needs of caring for one's family often make prioritizing health needs nearly impossible.[4]

Ultimately, this is a report about the experience of different racial, ethnic, and geographic populations, and examining them means that their experiences cannot be disconnected from their environments. One way to address this problem, at least partially, is with need-based measures that pertain to populations whose needs for care are as similar as possible. Controlling for health status can move us in that direction. Certainly, adjustment for socioeconomic status will be important in some areas where presenting data by race and ethnicity within income or educational groupings may help in interpretation. Whether income or education is more relevant to access and whether one of these should be a preferred measure of socioeconomic status will, of necessity, depend on the consistency and the reliability of the data and findings of future research (Gornick, 2000).

Cumulative Effects

The relationships between access to care and each of the key variables we have been discussing—ethnicity, insurance status, and rural residence—have been extensively examined. However, the

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[4] It is worth noting that both the stigma and the health consequences of being poor in an urban or a rural area often differ significantly. It is also important to keep in mind the wide variation in socioeconomic status within all racial and ethnic groups.

relationship between insurance status and access or outcome has usually been examined *controlling for race and ethnicity* or vice versa. Very few studies have examined the cumulative effects of these factors. A recent study has suggested that having a combination of variables may predict worse access or outcome than one alone. For example, being uninsured and Hispanic is associated with worse access than either alone (Burstin, 2001). The addition of rural residence to this mix has not been examined.

Managed Care

As noted above, managed care provides unprecedented opportunities to define a denominator population and to monitor its utilization, quality, and outcomes. It is probably premature to measure its effects on access in rural areas. The challenges posed by racial and ethnic data in managed care plans have been discussed above. Nonetheless, two data sources can provide information on access for racial and ethnic minorities in managed care. The HEDIS measures for any use, mammography, and components of diabetes and mental health care are readily available from Medicare+Choice plans, and racial and ethnicity data can be obtained by linking to Social Security data. Recent analysis indicates that disparities remain quite substantial across all plans (Schneider et al., 2001). CAHPS data are available for both Medicare+Choice enrollees and the commercially insured population through the National CAHPS Benchmarking Data Set. The instrument includes a self-reported measure of race and ethnicity, measures of any use, use of a specialist, and need to see a specialist. Data for both populations, even when adjusted for socioeconomic status, indicate significant disparities across all plans. They also indicate large plan-to-plan variation in the degree of disparities, highlighting the heterogeneity among health plans (Lurie et al., 2002). A significant problem with CAHPS is the inability to examine response rates, particularly those for different racial, ethnic, or geographic populations.

Managed care has the potential to reduce disparities by focusing on denominator populations. Alternatively, it has the potential to worsen them if cost control efforts create differential access barriers; if providers engage in differential advocacy; or if there are problems navigating the system. These issues are well described elsewhere (IOM, 2002b). There is still debate in the literature about which aspects of managed care are most important to measure, for example, capitation versus other payment mechanisms, gatekeeping, and restrictions on provider choice. However, each is relevant to examining disparities.

Undercounted Populations

Two distinct populations of high need can significantly skew assessments of need for both care and access. Minority populations, particularly African Americans and Hispanics, are incarcerated at much higher rates than Whites, often due to differential sentencing for drug-related convictions (Iguchi et al., (in press)). Currently, most population-based measures of access, including insurance status, do not include those who are incarcerated. This has led to serious undercounts of the uninsured in some areas, particularly African American and Hispanic men. Access to care in prisons is highly variable, as is access to insurance after release. Most parolees do not get jobs that provide health insurance. In some states, they are ineligible for Medicaid.

Other populations that are seriously underrepresented when it comes to assessing access to care or insurance status are undocumented immigrants and the homeless. Many do not appear in the census or in surveys, yet they have substantial unmet health needs in both urban and rural areas.

Utilization as a Measure of Access

Some utilization measures that have long been considered indicators of access have been the subject of significant criticism, largely because they are felt to reflect preferences for care as much as unmet need. It has been argued that most people who are uninsured do not need or want insurance, although data consistently indicate this to be a small percentage of the uninsured. The issue is similar when examining the proportion with no visits, without a usual source of care, or without follow-up. When examined, only a small proportion of those without a usual source of care do not want one. The case of children and vulnerable adults is a special one. The adult acting on their behalf may not bring them for care for reasons unrelated to need. In these cases, the access barrier is often intrinsic to their caregiver. Some differences in utilization are believed to represent overuse by the White population. As is the case with socioeconomic position, stratifying measures by health status permits comparison of populations with similar needs.

Use of emergency departments for nonacute, first contact care is a slightly different issue. Care can, in fact, be obtained through emergency departments, and by law, emergency departments cannot refuse to see a patient. Increases in emergency department use are, in part, a function of not having an alternative place to go, not wanting or needing a regular provider, and convenience (Asplin, 2002). This leads some to suggest that emergency department use is an expression of preferences rather than an access problem. From a policy perspective, this is probably not a desirable utilization pattern. Emergency department overcrowding has become a significant national concern, and as such, impedes access for those who truly need emergency care. Furthermore, when people seen in emergency departments are offered a primary care visit within a short time, most choose non-emergency department care (Baker et al., 1991; Bindman et al., 1995).

For chronic disease, it is likely that utilization patterns reflect a combination of access and quality as is the case for a set of quality indicators for follow-up care or receipt of tests such as eye exams for diabetes. This kind of utilization clearly depends in part on aspects of quality such as recommendations made by the provider or system for follow-up care, or the system's ability to prompt the physician to provide—and the patient to obtain—needed care. Patient follow-up is also likely to be a function of patient-centered issues such as the quality of communication and the ability to understand the care plan. However, we must be careful not to assume that access ceases to be a barrier once a patient has entered the system, particularly for chronic care. Co-payments frequently pose barriers to obtaining needed follow-up care, as do other barriers such as transportation. While it is impossible to disentangle access and quality, chronic disease related-utilization should be a part of measuring access, particularly when examined in relation to need.

A final challenge in considering utilization as a measure of access relates to cultural factors that influence care seeking. A person's cultural beliefs (whether from a different country or a rural community) might lead to different definitions of illness or need for care. In that case, many would argue that lack of care does not reflect barriers to access. However, factors such as the inability of the patient and provider to speak the same language, lack of trust, fears of discrimination or fears of disrespect of one's culture, a prohibition of care for a woman by her male partner, along with discrimination or a lack of cultural sensitivity on the part of the provider all constitute cultural barriers that are reflected in utilization patterns. There are no easy solutions to these problems. Utilization measures must be interpreted with these issues in mind.

4–5. PRINCIPLES GUIDING MEASUREMENT OF ACCESS IN THE NATIONAL HEALTHCARE DISPARITIES REPORT

Outlined below are key principles that should guide the development of access measures for the NHDR:

1. Every effort should be made not to marginalize the NHDR. This can be accomplished, in part, by assuring compatibility with the National Healthcare Quality Report, and by using, when possible, its conceptual framework for reporting on access-related quality measures. Because equity is such a fundamental component of quality, it is expected that many quality measures will be reported by racial and ethnic subgroups. Some overlap between disparities in access and quality measures should be expected, but it would be highly desirable to use similar reporting formats.
2. The NHDR should be anchored in well-accepted, extant measures of access for which data are regularly collected. This will avoid the need to create and validate measures, an expensive and time consuming process. It will also link the NHDR to other reports and sources that use these measures and support its continuity from year to year.

3. As recommended by Fiscella, measures should address access issues that are particularly relevant for minority or rural populations (Fiscella, 2002). These measures should be relevant for the general population, but they should focus on areas in which disparities are likely to exist. In addition to general population measures, the committee should identify a set of measures for which access to quality care is particularly (but not solely) relevant to minority populations. Language access may be such an example.
4. Prevalence and contribution to morbidity and mortality should guide selection of these conditions. The 1998 Federal Initiative to Eliminate Racial and Ethnic Disparities in Health has focused on six clinical areas, all of which meet these criteria (CDC, 2000). They are infant mortality, immunization (child and adult), diabetes, cardiovascular disease, cancer screening and treatment, and HIV.
5. While the report should be anchored in a core of existing measures, new measures are sorely needed and should be developed for use in subsequent reports. These should account for the trends described above, including increase in chronic disease, a broader definition of health, and a recognition that factors outside of the immediate delivery system have major effects on access.
6. Data sources for this report will be an important consideration. Although reliance on federally collected data is most desirable, it is possible that reductions in funding for some kinds of data collection will seriously impair the ability to use necessary data. To assure that this report will provide important information about disparities in access, criteria for the use of data collected with nonfederal funding from such sources as foundations and professional societies should be considered.

4–6. CORE MEASURES

The set of core measures traditionally considered to measure access should form the basis of this report. They are well accepted and relevant for all populations. All of them reveal disparities. Specific issues related to their use are discussed below.

Insurance Status

That insurance is often a prerequisite to receiving care has been thoroughly documented. Disparities in the presence and type of insurance are also well known, as are the associations among insurance status and utilization, quality, and health outcomes. The presence of any insurance coverage should remain a core measure. Measures of underinsurance should be developed for future use and are discussed later. Issues related to the uninsured are the subjects of a separate, ongoing IOM project (IOM, 2002a).

Methodological issues in the reporting of insurance status must be considered. These are relevant regardless of whether the focus is on racial and ethnic disparities or on the general population. First, multiple federal and private data collection efforts assess insurance status. Each asks the questions slightly differently, and the wording of some of the measures has changed over time, leading to different estimates and frustration for policy makers (Berk and Schur, 1998). The Current Population Survey (CPS) has added a validation question to its measurement of insurance status, and this has lowered estimates of the uninsured in many states and made time trends difficult to interpret (U.S. Bureau of the Census, 2002b). Measures of insurance status are well summarized in Table B1 of *Coverage Matters* (IOM, 2001a). The NHDR would be best served by choosing a measure that is likely to remain stable over time.

While the absence of insurance has repeatedly been demonstrated to inhibit access to care, relationships between other aspects of insurance coverage and access are more complicated. Even in the presence of insurance, most Americans face co-payments, deductibles, and other degrees of cost sharing. Many have policies that do not cover primary and preventive care or medications. The latter is a particular feature of Medicare. Based on a definition proposed by Bashshur et al. (Bashshur et al., 1993), underinsurance can be characterized as “a situation in which the consequences of having less than full coverage are so burdensome that they inhibit realized access to needed care likely to result in the best possible outcome.” Bashshur et al. distinguish structural elements of underinsurance (for example, benefit packages), experiential elements (for example, degree of out-of-pocket coverage or part-time coverage), and perceptual elements (for example, the assessment of the insured individual about adequacy of coverage). Thus, underinsurance must be defined relative to a standard and does not necessarily mean having to pay for all or some portion of care. Because primary and preventive care are necessary for staying healthy, underinsurance can be said to exist when coverage for these services are not included in a benefit package. Similarly, underinsurance exists when essential medications are not covered although this is the current standard for many plans, including Medicare. While some authors have defined specific levels of out-of-pocket payment relative to income that constitute underinsurance, that level likely varies with income, making a uniform definition difficult. Use of a uniform standard could thereby be misleading, particularly when considering underinsurance for groups who, on average, have different incomes. It may be most useful to present information about premiums, covered benefits, any co-payments, and any deductibles for different races and ethnicities by income groupings, thus allowing the reader to further interpret the data and avoid the pitfalls discussed above.

Proportion of Adults and Children without a Visit and Their Health Status

These measures of utilization are often considered to measure access to care. General problems with utilization measures have been described above. Most guidelines call for young children to have preventive visits at least annually (or at least biannually for adolescents). However, apart from certain screening services, standards are not so clear for healthy adults. While insurance status is one predictor of foregoing a visit, minorities are less likely than Whites to have any visits, even within insured populations. In these cases, insurance is not a major determinant of use. Lack of visits may also reflect lack of need (real or perceived) or desire for care, or other predisposing and enabling barriers such as language, culture, or geography. The interpretation of “no visits” is less likely to be problematic for those with chronic health conditions or those in worse health. Nonetheless, data on whether or not a visit was obtained are easily available and reliable to the extent that racial and ethnic data are accurate. Stratifying by health status will help with interpretation of the data.

Regular Site of Care and Regular Provider

Measures of access have traditionally included measures of continuity of care and primary care, usually embodied in having a regular site of care or regular provider. The controversies around these measures relate primarily to the small number of individuals who do not want a primary provider, and the debate about whether a regular provider is as important as a regular system. In several studies, lack of a regular site and/or provider were the primary reasons for not seeking care when needed (Ettner, 1999). Additional studies show that both measures contribute independently. As managed care continues to evolve, attributes of the system may become more important than having a regular provider. These measures are readily available from national surveys, and the bulk of the evidence suggests that they continue to be useful, particularly if conditioned on health status.

IOM Indicators

The 1993 IOM report identified a series of access indicators important to quality or outcome-related objectives. These are discussed briefly.

Measures Related to Birth Outcomes

Although recent studies have questioned the relationships between prenatal care (particularly the amount) and birth outcomes, they may reflect that we are victims of our own success. As it is evermore possible to save babies born at increasing levels of prematurity, the number of low birth weight babies has continued to rise. Other poor outcomes, such as maternal transmission of HIV or congenital syphilis, remain strongly linked to prenatal care. Fortunately, rates of both have decreased dramatically. Hence, measures of adequacy of prenatal care continue to be relevant.

Immunization

High levels of immunization for vaccine-preventable illness remain important public health goals. However, several factors should be considered in the selection of immunization measures. First, as the vaccination schedule becomes more complex, we are likely to see greater disparities in the use of some of the newer vaccines. This raises the question of whether being up-to-date on diphtheria, pertussis, and tetanus (DPT)+polio+measles, mumps, and rubella (MMR) is the right measure, or whether uptake of newer vaccines (hepatitis B series, Hib, and conjugate pneumococcal vaccines) are measures that are more likely to reflect ongoing disparity challenges. The quality movement teaches us that measurement is important in improving performance. An unintended consequence of switching measures may be less vigilance in the public health and provider community for achieving high rates of coverage. Second, an increasing number of parents are choosing not to immunize children for reasons unrelated to access. Whether these numbers are large enough to affect population-wide rates and whether this phenomenon varies by race and ethnicity is unclear. Third, we now recognize that immunization is as essential for adults as for children, and that adult immunization rates are lower than those for children. Both child and adult immunization remain important access indicators.

Early Detection and Diagnosis of Treatable Disease

Despite the recent controversy, receipt of mammography and receipt of Pap smears continue to be important measures of access to care. Data indicate that preferences and culture play relatively minor roles in not receiving these services. Additional potential measures in this category are suggested in Section 4–7.

Reducing Effects of Chronic Disease: Preventable Hospitalizations for Ambulatory Care Sensitive Conditions

Preventable hospitalizations for ambulatory care sensitive (ACS) conditions are most useful as measures of access when used alongside hospitalization for conditions not associated with access to care. ACS admissions are a function of access to care (they occur more often among low income and uninsured populations), quality of care, and factors that are less related to the health care system. These data are usually examined with regard to geography, and ACS admissions are more concentrated in low-income areas. The challenge is to have enough knowledge about the denominator to be able to interpret the numerator. To the extent that the denominator (by race, ethnicity, and socioeconomic status) can be derived from census data, ACS admissions are probably useful measures of access. They do not, however, address other sources of regional variation such as practice patterns. Several methods to address this issue, such as creating ratios of ACS to non-ACS admissions, appear promising, but they need additional validation prior to use in a national report (Billings, 2002).

Reducing Morbidity and Pain through Timely Treatment

As suggested above, annual dental care visits remain an appropriate measure of access to oral health care, and there is broad agreement on the need for annual visits at the very least. Furthermore, oral health care is known to be associated with profound disparities by race, ethnicity, and geography. Examining reports of delayed care when needed continues to remain an important way to measure access. A need-based measure (such as care for serious symptoms) would be ideal, but data are not consistently available. As an alternative, it would be useful to stratify this measure by those in fair or poor health to allow further inferences about timely treatment for exacerbations of chronic disease. While access for those usually in good health is also a concern, this information is harder to interpret absent a need-based measure (IOM, 1993).

4–7. SUGGESTIONS

This section makes suggestions in four categories: 1. existing measures; 2. measures that can be readily constructed with currently available data; 3. measures that can be constructed with currently available data, but that need to be pilot tested and/or validated; and 4. measures that need to be developed.

1. Existing measures

The following core measures should continue to serve as a foundation for the NHDR:[5]

1. Presence of any insurance.
2. Usual source of care and provider, stratified by health status.
3. Proportion of children and adults with no visits, stratified by health status.
4. Proportion needing care and not getting it, stratified by health status.
5. Preventable hospitalizations for ambulatory care sensitive conditions for both children and adults, provided denominator data are suitable.
6. Adequacy and timeliness of prenatal care.
7. Rates of congenital syphilis.
8. Childhood immunization.
9. Proportion of children and adults without a dental visit.
10. Proportion of women over age 50 with/without a mammogram or proportion of adult women with/without a Pap test (adjusted for hysterectomy status).

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[5] The need for stratification of the second, third, and fourth measures by health status has been discussed above. There is much less disagreement about the need for care for those in worse health. In the case of childhood visits or immunizations, one could still consider utilization patterns a matter of parental preferences. However, as discussed earlier, children who do not get care that is generally felt to be needed may still be experiencing access barriers, even if their caregivers account for their lack of access. Rates of congenital syphilis have been declining, but they are higher than rates of perinatal HIV. Measurement should continue until rates have decreased by another 50 percent or until a new measure is identified.

2. Readily Constructed Measures

The following describes some new measures that can be readily constructed from existing data. In addition, the literature supports their use as indicators of access or access-related quality. New measures can also be readily constructed from existing data on consumer perspectives on care (staying healthy, getting better, living with illness or disability, and coping with the end of life) that are part of the NHDR's framework. These are described below.

Insurance

In addition to the presence of any insurance, the following measures are important in understanding disparities in insurance status: presence of part-time coverage, any coverage for primary/preventive care or medications, any co-payment, and any deductible. As discussed above, the cost-sharing measures should be stratified by income within racial and ethnic groups.

Staying Healthy

1. Rates of neonatal transmission of HIV.
2. Proportion of children with screening provided by Medicaid's Early Prevention, Screening, Diagnosis, and Treatment (EPSDT) Program.
3. Distribution of housing with lead paint that has not been rehabilitated.
4. Proportion of adolescents with no visit and their health status.
5. Proportion of adolescents with up-to-date vaccinations.
6. Proportion of adults with pneumococcal or influenza vaccines.
7. Deaths from pneumococcal pneumonia.
8. Deaths from complications of influenza.
9. Rates of colon cancer screening by flexible sigmoidoscopy or colonoscopy.
10. Proportion without a blood pressure check in past two years.

11. Proportion without cholesterol screening.
12. Proportion of individuals with ESRD whose first presentation is for dialysis.
13. Proportion of adults who are edentulous.

It should be noted that rates of neonatal HIV transmission could easily be examined and are related to the goal of promoting good birth outcomes. However, those rates have fallen rapidly and probably do not provide additional information about comparatively higher rates of congenital syphilis.

For the consumer perspective of staying healthy, a goal of promoting healthy development should accompany the goal of promoting good birth outcomes. This would include measures of developmental screening and screening for lead (see below). Measures of lead prevalence and screening have the advantage of addressing a community health issue, which ultimately is access to lead-free housing.

Immunization is an issue for adults as well as for children. Currently, racial and ethnic disparities in adult immunization are significantly greater than those for children.

Preventing complications of disease through early detection and treatment continues to be a major goal of care. Currently, cancer screening for women is the most widely accepted measure, and monitoring cancer screening rates has done much to increase them. Colon cancer screening should be added to this list because it affects men as well as women and is a costly procedure in the absence of health insurance. Some would argue that nonreceipt of these tests is largely a reflection of personal preference. However, it remains the case that the most common reason they are not done is lack of physician recommendation, which has been shown to be an area in which disparities occur.

Cancer screening is not the only way to prevent complications. Avoiding complications of chronic diseases such as diabetes can be achieved with access to high quality care. However, this requires that individuals know they have the condition and that they need care. This is the case for chronic diseases such as diabetes and heart disease. While additional measures need to be developed, data on hypertension screening and cholesterol awareness are currently available from the Behavioral Risk Factor Surveillance Survey (BRFSS). These measures would reflect the role of community/public health in identifying the need for care that triggers attempts to access the system as well as quality for those in care. Because chronic renal failure is such a prevalent condition among some minority populations, examining incident cases of renal failure whose first presentation is dialysis would be a similar indicator.

Finally, the proposed measure for oral health care (percent of adults who are edentulous) serves to assess a community-level factor and to reflect long term access to quality dental services.

Getting Better

1. Rates of knee or hip replacement for arthritis among Medicare beneficiaries.
2. Receipt of thrombolytic therapy for an acute myocardial infarction (AMI).
3. Rates of admission or readmission for serious mental illness after first diagnoses.
4. Proportion of admissions for mental health care without a follow-up visit in 30 days.
5. Rate of suicide.
6. Proportion of those needing mental health or substance abuse treatment who did not receive it.
7. Breast cancer survival, adjusted for stage at presentation.

The first two measures examine access to effective but costly care, and both are known to be associated with disparities. Timeliness of thrombolytic therapy is also important. A private data source collects this information (National Registry of Myocardial Infarction, 2002), and it is not available in recurrently collected federal datasets. The mental health measures examine the supply of mental health providers in a community (there are fewer in minority and rural communities) and unmet need. Admission for serious mental illness, like admission for asthma or heart failure, is largely avoidable through access to high quality care. Finally, rates of suicide serve to reflect community levels of depression awareness as well as access to mental health services. Suicide rates among Native Americans are quite high, and they are increasing rapidly in African American men. It will be important to adjust for regional differences in suicide rates when making these comparisons. In the long run, rates of successful and unsuccessful suicide attempts would serve as a better measure, but such a measure needs further development. One exception would be for adolescents, where data on suicide attempts are reported through the Youth Risk Behavior Survey (YRBS).

The proposed measures regarding substance abuse reflect the importance of this problem for the population as a whole, the reported disparities in access to substance abuse treatment, and the particular role that substance abuse plays in the HIV epidemic.

The proposed breast cancer measure reflects the fact that the gap in screening between African Americans and Whites has been largely closed. Adjusting for stage at diagnosis also permits examination of populations with similar needs. Because equal treatment is felt to lead to equal outcomes, this measure likely reflects access to high quality care.

Living with Illness or Disability

1. Proportion of HIV-infected individuals who know their status.
2. Proportion of HIV-infected individuals who know their status and are receiving care.
3. Proportion of ESRD patients referred for transplant evaluation or receiving renal transplant.
4. Proportion of Medicare patients admitted for heart failure or acute MI who saw a specialist.
5. Proportion of diabetics who received an eye or foot exam from a health professional.
6. Proportion of diabetics who saw a nutritionist for counseling.

7. Availability of Medicaid coverage for older adults below 200 percent of the Federal Poverty Limit (FPL).

The HIV epidemic has a disproportionate impact on minority communities. These proposed measures reflect access that is dependent on the functioning of the public health system as well as entering and remaining in the health care system itself. Disparity in access to specialty services for people with chronic disease is a well-documented problem. The issue of renal transplantation was previously discussed. Use of this specialty measure for heart disease obviates the need to risk adjust to examine differential use of procedures. The diabetes measures reflect the evolving needs for disease management and team care. Diabetes is the recommended disease entity here because disease management has been best studied for this condition. In addition, there is a high prevalence of diabetes in Hispanic, Native American, and African American populations. As discussed, insurance coverage for low-income elderly with chronic disease remains a serious access issue.

Coping with the End of Life

1. Proportion of Medicare beneficiaries with death from a cancer diagnosis who received hospice services or home care in the last six months of life.
2. Proportion of those covered by Medicare or Medicaid who died from HIV and who received hospice services in the last year of life.
3. Proportion of Medicare beneficiaries receiving care in a skilled nursing facility in the last year of life.
4. Availability of Medicaid coverage for older adults below 200 percent of the FPL.

Unfortunately, all of these potential measures are based on kinds of utilization that are likely to reflect personal and cultural differences in preference for end of life care, and they will need to be interpreted in that light. Contrasting patterns of end of life care for cancer and HIV will enable examination of disparities in care for conditions with different degrees of social acceptance.

Indicators Relevant to the Entire Continuum of Care

1. Racial and ethnic distribution of matriculating medical, dental, and nursing students.
2. Proportions of racial, ethnic, urban, and rural populations with Internet access.
3. Literacy, especially health literacy.

Issues related to a diverse workforce are discussed above. Information regarding Internet access is available through the Department of Commerce and can serve as an indicator of access to information, especially since this will be a major vehicle for obtaining information in the future. The Department of Education is scheduled to begin data collection in the summer of 2002 on the National Assessment of Adult Literacy Survey (NAALS). A question regarding access to care is currently planned. This will facilitate further understanding of the relationships between literacy and access, as well as provide a direct assessment of literacy.

3. Other New Measures

Existing data could also support measures on important aspects of access, but these will require pilot testing and/or validation. The following lists those measures and briefly describes ways that they could be tested and/or validated.

1. Proportion of children on Medicaid who are screened for elevated lead levels.
2. Proportion of people with diabetes who first present with end organ damage.
3. Accessibility of a mental health provider.
4. Proportion of the population who needed mental health care or substance abuse treatment, but who did not receive it.

Lead screening is now a Medicaid requirement, and this information is, in theory, available from state Medicaid programs. Work will be required to examine the reliability of this information prior to use. The diabetes measure can presumably be obtained for the

Medicare population by examining new diabetes diagnoses and secondary diagnoses reflecting end organ damage within a specified time frame after diagnosis. Validation of the measure could be accomplished through chart review or potentially through linking with data from the National Health and Nutrition Examination Survey (NHANES) and Medicare. Geographic accessibility of mental health providers can theoretically be determined by mapping community demographics, community mental health centers, and information from professional societies. However, this cannot provide information on wait time to appointment, whether providers are taking new patients, the number of patients who have Medicaid, or the number of patients who are uninsured. Nonetheless, the presence of providers in a community is a prerequisite to actually getting an appointment. Information about language capability of mental health professionals is available from health plans and professional societies.

Proposed measures and probable data sources appear in Tables 4–2 through 4–4.

4. Measures That Need to Be Developed

Measures most in need of development are those that reflect patient-centered aspects of care, culture, and the community role in access to care. These are described below.

Stereotyping/bias/discrimination. These factors may account for racial and ethnic differences in care. While this has been easier to measure in other settings such as housing or banking in which testers can be used, it is more difficult in the health care setting. This issue was the subject of a recent conference at the National Institutes of Health (NIH) on measuring bias and discrimination in health, but no consensus was reached regarding which measures to use. Recently, the Commonwealth Fund released a study reporting on the frequency of perceived discrimination in the health care setting. Analysis of the relationships between those items and measures of access to care is underway. A related issue is trust, which is relevant for both the individual provider and the system overall. Here, some measures have been developed, and these show quite divergent levels of trust, at least between Whites and African Americans. However, these are not widely used, and further development is necessary.

TABLE 4–2 Staying Healthy

MEASURE	PROPOSED SOURCE
Rates of Neonatal Transmission of HIV	Centers for Disease Control and Prevention (CDC)
Proportion of Children with EPSDT Screening	Centers for Medicare and Medicaid Services (CMS)
Proportion of Children Screened for Elevated Lead Levels	CMS
Distribution of Unrehabilitated Housing with Lead Paint	Department of Housing and Urban Development (HUD)
Proportion of Adolescents with No Visit and Their Health Status	Youth Risk Behavior
Proportion of Adolescents with Up-to-date Vaccination	CDC
Proportion of Adults with Pneumococcal or Influenza Vaccine	Behavioral Risk Factor Surveillance System (BRFSS)
Deaths from Pneumococcal Pneumonia	CMS, Health Cost and Utilization Project (HCUP)
Deaths from Complications of Influenza	CMS, HCUP
Rates of Colon Cancer Screening by Flexible Sigmoidoscopy or Colonoscopy	CDC, BRFSS
Proportion without a Blood Pressure Check in Past Two Years	BRFSS
Proportion without Cholesterol Screening	BRFSS
Proportion of Diabetics Who First Present with End Organ Damage	CMS, National Health and Nutrition Examination Survey (NHANES)
Proportion of Individuals with End Presentation of Dialysis	ESRD
Proportion of Adults Who Are Edentulous	National Health Interview Survey (NHIS)

TABLE 4–3 Getting Better

MEASURE	PROPOSED SOURCE
Rates of Knee or Hip Replacement for Arthritis among Medicare Beneficiaries	Centers for Medicare and Medicaid Services (CMS)
Receipt of Thrombolytic Therapy for an Acute Myocardial Infarction (AMI)	CMS
Mental Health Provider Accessibility	Center for Mental Health Services (CMHS)
Proportion of Population Who Needed Mental Health Care But Did Not Receive It	CMHS
Rates of Admission for Serious Mental Illness	CMS
Proportion of Medicare Admissions for Mental Health Care without a Follow-up Visit in 30 Days	CMS
Rate of Suicide	National Center for Health Statistics (NCHS)
Proportion of Those Needing Substance Abuse Treatment Who Did Not Receive It	Substance Abuse and Mental Health Services Administration (SAMHSA), Organization of American States (OAS)
Substance Abuse Provider	National Household Survey on Drug Accessibility, SAMHSA, OAS
Breast Cancer Survival, Adjusted for Stage at Presentation	Surveillance, Epidemiology and End Results (SEER), CMS

Cultural competency. While measures that examine the cultural proficiency of the individual provider and of a health care institution are currently under development through funding from Health Resources and Services Administration (HRSA) and the California Endowment, a generally accepted, consistent, and operational definition of cultural competency is still needed. To be most useful, measures should be validated and have a clear and demonstrable relationship to access and outcomes.

TABLE 4–4 Living with Illness or Disability

MEASURE	PROPOSED SOURCE
Proportion of HIV-infected Individuals Who Know Their Status	Centers for Disease Control and Prevention (CDC)
Proportion of HIV-infected Individuals Who Know Their Status and Are Receiving Care	CDC
Proportion of ESRD Patients Referred for Transplant System Evaluation or Receiving Renal Transplant	United States Renal Data System (USRDS)
Proportion of Medicare Patients Admitted for Heart Failure or Acute Myocardial Infarction (AMI) Who Saw a Specialist	Centers for Medicare and Medicaid Services (CMS)
Proportion of Diabetics Who Received an Eye or Foot Exam from a Health Professional	CMS
Proportion of Diabetics Who Saw a Nutritionist for Counseling	CMS
Availability of Medicaid Coverage for Older Adults below 200% of Federal Poverty Level (FPL)	Current Population Survey (CPS), CMS

Language access. The Office of Civil Rights in the Department of Health and Human Services (DHHS) has promulgated standards for language access, but there are not yet regularly accepted ways to assess this. Both institutional and patient-reported measures are critical since this is one of the more actionable domains of access. New measures should be based on considerations of whether language access is available and, if so, the extent of its quality.

Measures of community/public health contribution to access. The need for these measures to assess performance of the public health system and the role of communities has been discussed above. Topical areas might include comparisons of estimated incidence of disease in a community or population to actual rates of detection/reporting, measures of awareness and health information in communities, and measures of community beliefs and values. Many would argue that access at a community level to resources associated with underlying causes of disease ought to be included in a report about disparities in access. These might include levels of educational attainment, employment, housing quality, or access to supermarkets.

Measures of access to specialty care and to disease management services. As chronic diseases become more prevalent and complicated to treat, access to specialty care may be necessary to achieve the best possible outcomes. Utilization measures are fraught with the problems described above. Self-reported measures can be constructed from CAHPS measures on the need to see a specialist and whether one was actually seen. However, these measures rely on the patient's understanding of whether specialist care is needed and therefore may not be ideal. As in the HIV and renal transplant examples, not knowing that care is needed is a major barrier to access. With regard to disease management, utilization of specific services common in disease management programs (for example, podiatry or physical therapy) can be examined with claims data. However, comprehensive disease management cannot.

Better need-based measures of access to mental health and oral health care. While these measures should be applied across the lifespan, the current Youth Risk Behavior Survey offers an opportunity to apply them to adolescents. Currently, measures of depression and suicidal ideation are collected, but mental health use is not. A measure combining rates of successful and unsuccessful suicide attempts would also be useful.

Better need-based measures that are both general and disease specific. The importance of such measures has been discussed above. Priority should be given to the development of need-based measures for conditions that are prevalent in minority populations and that contribute significantly to the burden of morbidity and mortality.

4–8. CHOOSING AMONG POTENTIAL MEASURES

Given the need to develop new measures, measures should be selected in three groupings. First, the traditional core measures should continue to be used. Ultimately, new measures should fulfill the following criteria:

1. They should represent issues that affect all populations, but that affect minority populations in an important way. For disease-specific measures, priority should be given to those conditions that were the focus of the 1998 Federal Initiative to Eliminate Racial and Ethnic Disparities in Health.
2. They should cover the lifespan.
3. They should capture disparities that are known to exist.
4. They should add important information beyond core measures.
5. There is a strong likelihood that the health of minority populations would improve if the focus of measurement were addressed. It is also possible that addressing some foci would improve health for all populations without decreasing disparities. Because the primary aim is improved health, measures should not be discarded for this reason.
6. They are particularly important for specific populations, even if they are less salient to Whites.
7. They fill gaps in the quality framework, including the continuum of care, attributes of quality, or care over the lifespan.
8. They reflect patient-centered or community-centered aspects of access.
9. They incorporate an expanded definition of health. This is particularly important for mental health since it is an important co-morbidity for chronic diseases such as diabetes and etiologic in much care-seeking behavior.

Second, new measures should be selected from priority measures that do not involve substantial development. The following identifies the measure and explains the rationale:

1. Proportion of adolescents with no visit, and their health status. Adolescents would constitute a new age group for this measure.

2. Proportion of adolescents with up-to-date immunization status. Adolescents would constitute a new age group for this measure.
3. Proportion of adults with pneumococcal or influenza vaccine. Adults would constitute a new age group for this measure. In addition, these vaccinations are public health priorities.
4. Rates of colon cancer screening. This measure would extend the measurement of cancer screening to men.
5. Proportion without a blood pressure check. This measure would capture the contributions of the community as well as of the delivery system.
6. Proportion of individuals with ESRD who require dialysis at their first presentation. This measure would capture the contributions of the community as well as of the delivery system.
7. Proportion of HIV-infected individuals who know their serostatus. This measure would reflect the contribution of the public health system.
8. Proportion of children on Medicaid who are screened for elevated lead levels. This measure would reflect the interface between the community and the health system.
9. Rates of admission for serious mental illness after first diagnosis. This measure would expand the concept of health to include mental as well as physical illness.
10. Proportion needing mental health or substance abuse treatment who did not receive it. This measure would expand the concept of health to include mental as well as physical health.
11. Proportion of diabetics who received an eye or foot exam from a health professional or who saw a nutritionist for counseling. This measure addresses health care for a major chronic disease.
12. Insurance issues such as the availability of Medicaid coverage for low income seniors, the proportion of people with insurance that covers primary/preventive care and medicines, and the proportion of people whose insurance includes co-

payments and/or deductibles. This measure captures different dimensions of insurance coverage.

13. Racial and ethnic composition of the health care workforce. This measure captures a new dimension of access, the importance of which is explained above.
14. Literacy. This measure captures a new dimension of access, the importance of which is explained above.
15. Proportion of Medicare beneficiaries with death from a cancer diagnosis or HIV who received hospice services or home care in the last six months of life. This measure addresses end-of-life care, which is relatively neglected as an area of measurement (IOM, 2001c).

Lastly, work should begin on new measures in all of the areas discussed.

4–9. CONCLUSION

A combination of existing measures, measures that can be developed from existing data, and new measures should be included in the NHDR. When utilization measures are used as access measures, comparisons of groups with similar health needs will facilitate interpretation. Additional measures should be developed, particularly those representing the contribution of community and public health measures to access as well as those focusing on prevalent health conditions in minority populations.

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5

GEOGRAPHY AND DISPARITIES IN HEALTH CARE

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This paper examines how health status, access to health care, and health outcomes vary by geographic location. It also examines which aspects of location appear most to affect health care access, services, and utilization. There are clear geographic differences in health status that vary according to the level of aggregation. At the national level, overall mortality rates are much higher in the Southeast, the Appalachians, and parts of the Intermountain West (Pickle et al., 1996). That pattern changes for Black males to include very high rates in the urban East and Midwest. For White females higher rates cluster in the Midwest and Mississippi Valley. There are likewise differences among states that mirror regional patterns. Within states, differences are associated with areas with lower incomes, higher numbers of minority populations, and cultural and historical risk factor patterns that contribute to higher rates of morbidity and mortality. The same gradients can be seen within cities and counties where neighborhoods and census tracts reflect similar patterns of health disparities. These differences are both apparent and persistent when subjected to statistical controls and comparisons (Geronimus et al., 1999).

5–1. GEOGRAPHY

Geography is often thought of as the generation and interpretation of maps that describe the physical world. Geography is far more than that, but the physical description of boundaries has a great deal to do with how we view communities and how we construct society (Giddens, 1984). The physical aspects of a community are usually defined by boundaries that may have been developed for a specific public purpose, but that often create gradients that separate one population group from another. This can be apparent in zoning rules or in the creation of jurisdictions that have different systems of social support. Areas can also become different through social and economic processes that create regions or communities whose boundaries are essentially invisible.

When speaking of health, the domain of medical geography is most often invoked. Medical geography, however, is more aligned with the study of disease and disease diffusion without explicit consideration of other aspects of human interaction. The structure of health services and how people use health services in ways that reflect and create disparities are factors that span the human and the medical parts of geography. The discourse of the geographer involved in describing health care delivery and health status has become controversial within the discipline itself. While space and place in health care delivery are important, their structure and interpretation are, to some, irrelevant to practical decision making because they are the result of overwhelming social forces and power relationships. To others, a point of view that includes spatial and landscape perspectives can be useful for local purposes and for broader policy development (Mohan, 1998).

Nevertheless, the power of geographic comparisons and boundary setting is real in the policy world, and the application of policy is very sensitive to location and scale. As one leading researcher has observed:

> There is no agreement about how to best define a geographical area in terms of socioeconomic position or about which area-based measures of socioeconomic position are most informative, especially across multiple kinds of health outcomes (Krieger, 2002).

This paper does not contradict that conclusion, but does recognize that there are options for understanding the geography of health disparities as well as for implementing solutions. For example, regions, states, and localities are different in several ways. Regional differences show that history, environment, culture, and politics have combined to create disparities that cross state boundaries. Those regional differences—apparent in the Southeast, Appalachia, portions of the Intermountain West, and selected parts of the Southwest-point to the need for interstate collaboration or federal coordination and sharing of resources. Urban-rural comparisons do not reveal consistent patterns of disparity, but rural and inner city conditions tend to magnify differences associated with other social, economic, and health system characteristics. There are variations in rates of illness and access to appropriate care that reveal themselves in comparisons across states. These consistent variations imply that there are state-level policy levers that can be used to reduce disparities. Town, city, and county boundaries may describe communities that can develop solutions using local government or social, religious, or external systems.

The small area geographies used most often to depict health status are appropriate for identifying and verifying health status disparities. They include units of census geography such as tracts and block groups, counties, ZIP code areas, and clusters of ZIP codes. These can be used to construct service or market areas that contrast health outcomes and utilization for primary care, general hospital care, and tertiary care. But the level of intervention appropriate to specific patterns of disparity is not always coterminous with those boundaries. While we may identify disparities in rates using ZIP code areas or census tracts, it is not easy to mobilize an intervention based on those boundary sets. People do not feel a sense of "membership" or citizenship to such areas, and neither government nor the health care system is structured to act at those levels unless the boundaries identify real neighborhoods or communities.

There is no consensus on a fundamental unit of geography to use in measuring health and health care in the United States or elsewhere. There are many reasons for this, including the problems of relating individual events to population rates. However, the most important reason lies in the way in which health data are reported (Meade and Earickson, 2000). Data are compiled according to the political and administrative organization of governments and, to a lesser extent, society. Denominators in rates are most often expressed as the population of some political unit such as a state. It would be more clinically useful to express rates in terms of gender, age, or even occupation. Those relate more directly to health care delivery, to health status, and to outcomes for individuals.

5–2. INTERSTATE GEOGRAPHY

Interstate geography includes several different units commonly used to analyze health care delivery and service and to formulate health care policy. The following is a brief overview of two: regions and rural-urban areas.

Regions

Regional systems and structures have been developed to cope with health problems across state borders. They include the health care system development of the Tennessee Valley Authority (TVA) and the Appalachian Regional Commission (ARC) as well as work in the lower Mississippi Delta. The ARC remains active in this field and supports work that illustrates disparities in health status and access through the University of Kentucky (www.mc.uky.edu/RuralHealth/ARC_AHPAC/ahpac.htm). There are regional initiatives in the Mississippi Delta through various organizations and governments. A regional study of asthma supported by the Trust for America's Health is illustrative (health-track.org/reports/ms0420/). The Health Resources and Services Administration (HRSA) announced a program to improve health care by supporting rural hospitals in the Delta region in late 2001. Similar cross-state efforts such as the U.S.-Mexico Border Health Commission are underway along the U.S.-Mexico border (www.borderhealth.gov/). These regional initiatives are supported through affiliations of state governments such as the Southern Governors' Association or the Southern Growth Policies Board or ad hoc groups of governors or state agency heads.

Rural-Urban Areas

One view of the geographic structure of the nation contrasts how the population is distributed between cities and rural areas. There are more than 60 million people classified by the U.S. Bureau of the Census as "rural" and 55 million living in "nonmetropolitan" counties in 2000. This is a population group comparable in size to the United Kingdom. Rural America would be among the top 20 nations in population. The structure of the Congress, which gives equal representation to states in the Senate, means that the rural issues that are important in sparsely populated western states such as Idaho, Wyoming, Montana, and North and South Dakota are given careful consideration in Congress. The political as well as physical geography of the U.S. makes rurality an important concept.

The two most common designations of rurality used in describing populations are those of the U.S. Bureau of the Census and the U.S. Office of Management and Budget (OMB). "Urbanized areas" are defined by the U.S. Bureau of the Census according to a complex set of characteristics that takes into consideration the economic nature of a place, transportation patterns, and the number of people living in a fixed area. That definition is undergoing revision and a final rule is expected to be published soon. For the 2000 census, rural areas are considered places outside urbanized areas. Urbanized areas are composed of "core census block groups or blocks that have a population density of at least 1,000 people per square mile and surrounding census blocks that have an overall density of at least 500 people per square mile" (www.census.gov/geo/www/ua/ua_2k.html). This delineation has not been used often to determine effects on health and health care. More often the OMB Metropolitan-Nonmetropolitan classification of counties is used for comparisons.

The OMB designation classifies counties as metropolitan or nonmetropolitan based on whether the county has a large city and a number of suburbs. It also takes into account a functional element that measures the extent to which peripheral counties are economically integrated with their surrounding metropolitan counties. A Metropolitan Area (MA) must contain either a place with a population of at least 50,000, or a census-defined urbanized area and a total MA population of at least 100,000, or reflect the economic activities of such a place. Various attempts to subclassify the counties within the metropolitan and nonmetropolitan categories exist, and they have been used to examine health care resource use and distribution and health status. In 2001 the National Center for Health Statistics (NCHS) included a rural-urban comparison in its *Healthy People* series. The NCHS report found that:

- Residents of counties on the borders of large metropolitan areas generally are ranked highest on health indicators.

- Indicators of health, health care use, and health care resources can differ by level of urbanization.
- Regions do vary, which is reconfirmed by data.
- Nationally, residents of the most rural counties have the highest death rates for children and young adults, the highest death rates for unintentional and motor vehicle traffic-related injuries, and the highest mortality for ischemic heart disease and suicide among men (Eberhardt et al., 2001).

These general comparisons are plagued by the problem of aggregation of widely divergent nonmetropolitan populations and communities into large, gross classifications that are meant to be consistent across the nation. There are regional patterns of rural disadvantage that are highly discernible. For example, there is higher infant mortality in the rural Southeast. Those conditions are clearly related to the income and educational differences between those rural regions and other parts of the nation. Geographic patterns of morbidity and mortality vary by race and ethnicity (Albrecht et al., 1998), and these differences are sometimes reinforced by rural location. Blacks and Whites living in nonmetropolitan counties have higher death rates from diabetes (Ricketts, 2001) and heart disease (Slifkin et al., 2000).

The ecological interaction of income and health has been widely reported (Kawachi et al., 1997). A clear and consistent relationship exists between the two: the lower the income of the place, the worse the health status. The same has been found for the relationship of health to income inequality, but with less convincing evidence (Mellor and Milyo, 2001). However, when examining income inequality and health at the state level, one study found an interesting stronger relationship between inequality and self-reported health for nonmetropolitan residents (Blakely et al., 2002). That finding suggests that the structure of income inequality differs for rural areas, but it also might be an artifact of the clustering of respondents in nonmetropolitan counties.

Access to Care in Rural Areas

Access to health care services in rural versus urban areas has been explored by health services researchers for decades. Rural residents are, on average, poorer, older, and, for those under age 65, less likely to be insured than persons living in urban areas (American College of Physicians, 1995; Hartley et al., 1994; Braden and Beauregard, 1994; Schur and Franco, 1999). Rural Americans also report more chronic conditions and describe themselves in poorer health than urban residents. Further, injury-related mortality and the number of days of restricted activity are higher in nonmetropolitan areas. The degree to which lower levels of access affect health outcomes and utilization for rural persons is at issue, however, given the conclusions drawn by MedPAC in its *Report to Congress* (MedPAC, 2001). It is easy to challenge its flat assertion that an access gap does not exist. The analysis did not always include controls for health status, and the risk adjustment for prior use may have made the analyses inaccurate. The access study also did not differentiate between underserved and adequately served communities and did not reveal whether there was an independent rural or travel effect for the measures of access. But most importantly, the sample was drawn with the assumption that rural places compose a homogenous sample stratum. While the wide variation in access in urban systems is accepted and comparisons within and between metropolitan areas are usual in national surveys, this is not feasible for rural places given the current construction of these surveys (Schur et al., 1998).

Race, Ethnicity, and Rurality

The interaction of race and ethnicity and rurality has been examined in a review of studies of six conditions highlighted by the U.S. Department of Health and Human Services (DHHS) in its disparities initiative. The conditions are infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection, and child and adult immunizations (Slifkin et al., 2000). The review found that rural minorities are further disadvantaged compared to their urban counterparts in cancer screening and management, cardiovascular disease, and diabetes. The gaps between Whites and minorities appear to be greater for these conditions in rural places, but the studies that made up the review did not carefully control for many variables that might describe problems with access to care. Likewise, comparisons did not include controls for regional effects. There are clear limitations to drawing inferences from geographical classifications at the county level.

In sum, there is credible evidence that being in a rural place has a strong and relatively consistent negative effect on one's economic chances. However, there is some difficulty in creating a strong claim that rurality has an independent and significant impact on people's health. The problem, it seems, is that the definitions of what are rural and nonmetropolitan are more closely tied to factors related to population and its density. These have a consistent economic effect, but an inconsistent health effect. Unfortunately, a definition of medical rurality is not at hand. Instead, various measures of medical underservice, health professional shortages, and vulnerability are available. While those measures are place specific and tend to be more rural, they are also applicable to highly urbanized areas. The search for a perfect measure of rurality that will capture its health effects may be a useful exercise, but will require a careful analysis of the effects of distance, culture, occupational context, and the spatial characteristics of technology and information diffusion. Such a metric will have to overcome the strong bias in favor of existing, well-documented, and relatively consistent systems of classifications of rurality. To do so, it will have to have a transparent application to populations and health care systems as well as a clear application to policy.

Distance as a Proxy for Rurality

Distance to health care is one of the most important geographic features that may affect health status and health outcomes and that may contribute to disparities. The effects of distance on access to health care services have been a subject of research for some time. For example, Weiss examined how distance to a hospital combined with social class determines patterns of use (Weiss and Greenlick, 1970). Conner and colleagues examined studies of distance to care to attempt to find standards for access (Conner et al., 1994). While they found evidence of distance decay in use and some indication that quality of care suffered when care was provided to people who lived at some remove from services, they were unable to develop clear guidance for what would be a fair standard for physical accessibility. Nor were they able to develop clear guidance on how to measure it. They were able to contrast units of analysis classifying areas as “town/community/ZIP”; county; “market-share defined”; and national. However, they made no recommendations concerning their ability to detect differences that might reflect disparity. There is evidence that underserved populations are located at a greater physical distance from services in rural communities. Low-income populations in urban areas are often adjacent to a high density of health care resources (Bohland and Know, 1989).

5–3. INTRASTATE GEOGRAPHY

There are several geographic units that are often used to analyze health care delivery and services and to develop health care policy. The following briefly examines states, communities, local health department jurisdictions, census and postal geography, and market areas.

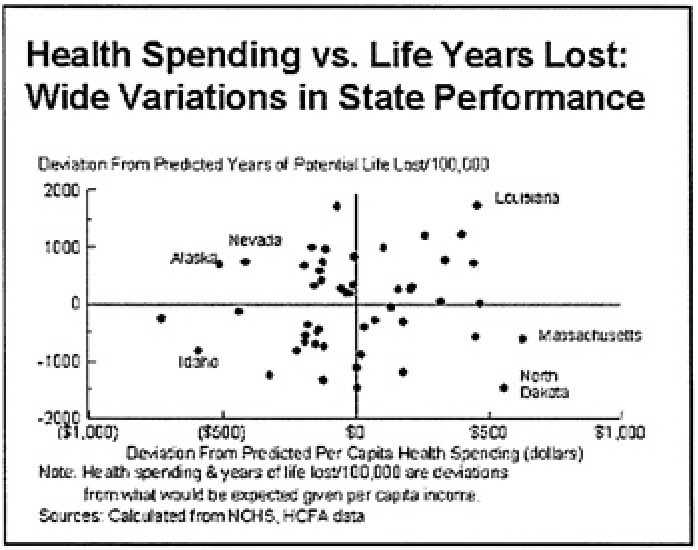
States

In the U.S., states are the fundamental polities for the support and regulation of most local health care delivery. When the federal government chooses to provide support for nationwide public health programs, each of its three major options involves the states:

- Grants-in-aid to states based on their populations, or so-called block grants;
- Formula grants that take into consideration some factors of need, with the Medicaid program an example of such a system; and
- Program or project grants that involve states either as umbrella applicants or as passive reviewers, with community health centers an example.

State public health systems and their vital and health statistics reporting systems provide much of the data on health care disparities. States have the primary responsibility for the protection of public health. As part of that responsibility, states have developed a coordinated system of data collection and reporting. They have also developed programmatic interventions that vary. State governments vary in the degree of support for public health and health care delivery, and there are differences in the structures of their health care delivery systems that are due to their respective populations, cultures, and histories. The states vary as markedly in investment in health as they do in health outcomes. Figure 5–1 describes a potentially close relationship between per capita health spending and years of potential life lost (YPLL).

FIGURE 5–1 Variations among States in Life Years Lost and Per Capita Spending for Health



SOURCE: (Conover, 1998. Reprinted with the author's permission.)

Key to the identification of a substantial difference in health status or access between geographically defined populations or population segments is the degree to which the boundaries separate or include the population that is negatively affected or the degree to which the nature of the area itself affects health and health care. Maps of the United States at the state level show strong and important differences in mortality, morbidity, and access to care measures. There are different ranking and ratings systems that reveal health disparities at the state level, including those distributed by the UnitedHealth Group (UnitedHealth Group, 2000), Morgan Quitno (Morgan and Morgan, 2001), the National Conference of State Legislatures (Siegel, 1998), AARP (Lamphere et al., 1999), and the Urban Institute (Liska, et al., 1998). The National Center for Vital and Health Statistics of the Centers for Disease Control and Prevention (CDC) does not explicitly rank states, but data it distributes can easily be ranked and grouped. Those rating systems are criticized for their inaccuracy and the inclusion of subjective judgments of what constitutes a summary measure of health (Gerzoff and Williamson, 2001).

There are other compilations of state-level data that allow for comparisons, but that do not specifically rank or rate states. These include the Kaiser Family Foundation "50 State Comparisons" web site (www.statehealthfacts.kff.org), state-level data that are compiled by the Maternal and Child Health Bureau in the Health Resources and Services Administration (HRSA) to track Title V progress (www.mchdata.net/), and a series of health profiles for states compiled by HRSA that covers a wide range of indicators (stateprofiles.hrsa.gov/StateProfilesIndex.html). State agencies and the public pay close attention to these rankings systems, and they are sometimes used to guide policy decisions. The UnitedHealth Group rankings are circulated widely and commented upon regularly. The indicators used in that ranking system have been modified slightly for use as a performance measuring system for the state of Nebraska.

States have attempted to lead in the implementation of comprehensive programs to improve health status and the coordination of services either through overt political reform or through administrative emphasis on health (Nelson, 1994). The degree of variation in state efforts to improve population health is illustrated by the variation of their policies. For example, the Robert Wood Johnson Foundation's State Coverage Initiative and its tracking of insurance coverage by states illustrates the range of coverage decisions and the potential for state-level policy to influence how health care is paid for (www.statecoverage.net/matrix.htm).

The comparison of state-level data is important and reveals differences in health status and in overall measures of access and use of services. Comparisons of the use of certain therapeutic strategies for Medicare beneficiaries revealed patterns at the state level that could be interpreted generally across regions. Jencks et al. found that Medicare beneficiaries in less populous states and those in the Northeast were more likely to receive appropriate care as measured by 24 process indicators than those in more populous and southeastern states (Jencks et al., 2000). These patterns are illustrated in the work included in the *Dartmouth Atlas of Health Care* and its companion publications (Dartmouth Medical School, 1998).

Communities

Current policy emphasizes targeting "communities" for interventions to improve health and reduce disparities (Dorch et al., 1997). The *Dictionary of Human Geography* defines a community as "[a] social network of interacting individuals, usually concentrated into a defined territory. The term is widely used in a range of both academic and vernacular contexts generating a large number of separate (often implicit) definitions" (Johnston et al., 2000, p. 101). The Robert Wood Johnson Foundation recently commissioned papers to explore the appropriate geographic definition of a community that would allow the optimization of programs to improve population health. According to the conclusions reached by its contractors,

> Community is a difficult concept to work with empirically and it has many, often overlapping, sometimes competing, definitions. Little consensus exists about boundaries or membership either in a general sense or in the context of measuring capacity for improving population health, or measuring a community's performance with regard to specific health status indicators. Race, income, sexual orientation, geography, and service areas, *inter alia,* are all viewed as valid parameters for defining a community (O'Keeffe et al., 2001, p. 23).

The relationship between socioeconomic characteristics and health in small areas has been described and validated in multiple studies at the census block group, census tract, and ZIP code levels

(Krieger et al., 1997; Krieger, 1992; Kwok and Yankaskas, 2001). The field of "small area analysis" has amply demonstrated that variations can be found, but the determination of what are unacceptable variations remains open especially for the investigation of health services and access to health care (Stano, 1991; Diehr et al., 1990; Diehr et al., 1992).

Natural Communities and Social Networks

"Natural" communities or natural areas are described by the activities of people living in a named place or neighborhood. There are empirical techniques for identifying and summarizing natural areas in geography and sociology. The geographic relationship between the health care-seeking behavior of people and the spaces they use for work, shopping, and leisure have been described using maps that show areas of higher potential and actual use (Gesler and Meade, 1988). Natural communities might emerge from secondary analysis of rates that show contrasts. These could be developed and compared using techniques of geographical and sociological analysis. The development of a "landscape of disparities" may be more of a visualization exercise than an empirical problem, but there is some movement toward using Geographical Information Systems (GIS) to relate problem locations to populations and population activity to suggestions for solutions (Rushton et al., 2000).

Epling, Vandale, and Steuart describe extended family networks as perhaps the most appropriate denominator for epidemiological characterization of populations because this would allow for "more efficient units of diagnosis and therapy" (Epling et al., 1975, p. 87). In this case the denominators and numerators used to determine disparities in health would be developed on the basis of kinship and connection. They suggest that the validity of the construction of household networks can be determined by testing the hypothesis that there is greater similarity of health and disease episodes and behaviors within distinct social networks than between them.

Social networks and social support are understood to be important in determining health status (Weissbourd, 2000). But the only tractable way to understand these ties that bind seems to be through anthropological and ethnographical study that involves primary data collection. There may be proxy indicators for family and community cohesion that are reflected in church attendance and membership or participation in family-focused activities through employment, schools, or recreation. These proxy measures then become community indicators rather than measures of individual family unit cohesion and are reflected in the extant measure of social capital. It might be, however, that there are strong ties within families, but weak connections to other families. This might fit the characterization of a "clan" structure in the southern Appalachians or strong ethnic divisions in an urban neighborhood.

Identifying the "Healthy Community"

The characteristics of healthy communities have been described by organizations like the Healthy Communities movement associated with the Civic League. Healthy communities, according to Norris and Pittman, exhibit seven patterns that unite mind, spirit, and body (Norris and Pittman, 2000). A community that is healthy shapes its future; cultivates leadership everywhere; creates a sense of community; connects people and resources; knows itself; practices ongoing dialogue; and embraces diversity. These characteristics would appear to reduce disparities. However, they raise the question of whether communities that have these characteristics as well as differences in health outcomes by race or other population groups should be considered to have the same degree of disparity.

In the recent past, the idea that "social capital" contributes to the capacity of a community to improve health has been proposed. As an example of a social capital index, Joshua Galper describes an empirical approach to clustering and ranking counties on the basis of their social or civic capital (Galper, 1998). His indicators include the structure of the local economy as indicated by, for example, the number of large firms; the payroll of membership organizations; the number of museums, gardens, and zoos; crime and unemployment rates; educational levels; the age distribution; and newspaper readership, among other variables. This grouping and ranking system is similar to that used in the article, "How To Build Strong Home

Towns" (Irwin et al., 1997). The Pew Charitable Trusts, the Population Association of America, and community and government agencies in Canada and Australia have also created approaches to measure social capital or community capacity (Pew Charitable Trusts, 1997; Teachman et al., 1997). These assessments of social capital have many of the same limiting characteristics that are encountered in community indicators of health care needs. They depend on fixed and often irrelevant units of analysis or denominators. These assessments are composed of indicators whose original purpose was to characterize some other element of the society or discrete activity. In addition, they are not very predictive of "outcomes," whether they are measured in terms of health status or economic performance.

Local Health Department Jurisdictions

One likely focus for the implementation of health-enhancing and disparity-reducing policies on a geographic basis is the local health department. However, only half of the states currently have local health departments that are controlled by local government (Turnock, 2001). Fifteen states have centralized systems with control over local health units exercised by a state health agency, and remaining states have some form of mixed or shared control. The population coverage for local health departments may be very small and local: one quarter of health departments are responsible for 14,000 people or less. Health department districts or units represent the local presence of public health, and these units have a responsibility for monitoring health status. It is less clear that these districts are responsible for measuring their capacity for affecting health. However, there are currently energetic efforts on the part of the CDC to promote the evaluation and assessment of the performance of local health departments (Halverson et al., 1998; Halverson, 2000; Mays and Halverson, 2000). These assessment measures for public health may provide some input for "actionability" since the health department is often a key element in identifying local health priorities and developing programs.

Primary Care Service Areas

In the delivery of health services, there is a prevailing belief that the fundamental unit for constructing a rational health care delivery system is the primary care practice. In the Community-oriented Primary Care (COPC) paradigm, these areas often become coterminous with public health target areas. Primary care practices staffed by a generalist physician or other primary care practitioner are, under this regionalized scheme, appropriate caregivers for the small village or community of 1,000 or so people.

Primary care service areas have been developed in several states including Arizona, California, Maine, North Carolina, and Tennessee. They are used for the analysis of access to care or to create subcounty areas for designation for federal programs. These are clusters of ZIP codes (NC) and sub-county census geography (AZ, ME, CA). The system used in California is perhaps the oldest continuously used system and may present a template for other states to consider in developing a set of communities of solution for health services at a geographic level that is appropriate to local action (Smeloff and Kelzer, 1981). Whether these areas represent communities of solution for health improvement has not been addressed. But their use in California and North Carolina in the examination of preventable hospitalizations points to a broader set of causal factors for health beyond health care (Ricketts et al., 2001; Bindman et al., 1995).

Hospital Service Areas

The determination of medical service areas became an important part of health policy considerations in the 1980s due to the attention paid to legal and economic issues surrounding competition (Morrisey et al., 1988; Morrisey, 1993). Geographic methods for health care service area construction were the subject of a comprehensive review in the context of geography (Simpson et al., 1994).

There are three major types of methods for creating service areas: geographic distance, geopolitical areas, and patient origins. A distance approach would create radii or ellipses that surround a central place or limited numbers of nodes that represent core activities. This method is appropriate where a legislature or a regulating agency wishes to set a general standard for access. For example, "all enrollees must have a primary care clinic or office within 30 miles of their home." These systems usually create a "crow-fly" or straight line standard, but occasionally travel time is used. Geopolitical boundaries are most commonly used to define health care service areas. This is largely due to their close links to policy-making bodies such as local and state governments that often operate health services or have public health responsibilities. The use of public funds is most often restricted to benefit-specific, pre-existing jurisdictions. Crossing those boundaries runs counter to the mutually exclusive nature of local government and its operations.

The use of patient origins to create service boundaries usually aggregates smaller geographic units such as ZIP codes or census tracts into areas using an inclusion rule based on proportion of total hospital admissions or hospitalizations from the small area. For the *Dartmouth Atlas of Health Care,* the Dartmouth Medical School team led by John Wennberg created an algorithm for the development of hospital service areas for the entire United States with the assistance of professional geographers (Dartmouth Medical School, 1998). There were 3,436 hospital service areas for the 4,900 general hospitals in the nation in the final service area map constructed for the *Atlas.* The *Atlas* and its derivative products are used for benchmarking many rates of treatment and resource allocation. The *Atlas* also provides data for the determination of comparative needs and points to important disparities in the health care system. The service areas that the *Atlas* uses may have the potential to serve as "communities of solution." It should be noted that the authors of the *Atlas* have not made this proposal. Nonetheless, the ubiquity of the *Atlas* may create a perception that these areas can be used for these kinds of analyses as more and more policy makers refer to it and its structure.

Census and Postal Geography

Key to the collection of denominator statistics for local health measurement are the census geographies used to organize the extensive data collected regularly by the U.S. Bureau of the Census. Table 5–1 lists political, census, postal, and special geographies, all of which are used for statistical reporting.

TABLE 5–1 United States Political and Statistical Jurisdictions

POLITICAL JURISDICTIONS	NO.	STATISTICAL REPORTING AREAS	NO.
States and Equivalent Entities	57	Regions	4
States	50	Divisions	9
District of Columbia	1	Metropolitan Statistical Areas (MSAs)	268
Outlying Areas	6	CMSAs (Comprehensive MSAs)	21
Counties and Equivalent Entities	3,248	PMSAs (Primary MSAs)	73
Minor Civil Divisions (MCDs)	30,386	Urbanized Areas	403
Sub-MCDs	145	Alaska Native Village Statistical Areas	217
Incorporated Places	19,365	Tribal Jurisdiction Statistical Areas	17
Consolidated Cities	6	Tribal Designated Statistical Areas	19
American Indian Reservations	310	County Subdivisions	5,903
American Indian Trust Lands	52	Census County Divisions	5,581
Alaska Native Villages	217	Unorganized Territories	282
Alaska Native Regional Corporations	12	Other Statistically Equivalent Areas	40
Congressional Districts	435	Special Economic Urban Areas	4,423
Voting Districts	148,872	Census Tracts	50,690
School Districts	16,000	Block Numbering Areas (now census tracts)	11,586
Neighborhoods (used only in 1980)	28,381	Block Groups	229,192
ZIP Codes	39,850	Tabulated Parts	363,047
ZIP Code Tabulation Zones (ZCTAs)	40,000	Blocks	7,017,427
		Traffic Analysis Zones	200,000

SOURCE: (U.S. Bureau of the Census, 2002).

One common geographic unit is the Zone Improvement Plan Code, or ZIP code. ZIP codes are not always bounded areas. They are, by definition, a collection of postal addresses aggregated to improve mail delivery. A ZIP code may be assigned to a single building, a post office, or an institution. ZIP codes that cover a defined area may be interlaced as one delivery route passes and even crosses another, although that is rarely the case. ZIP code boundaries and route aggregations change continuously and do not require clearance at a central national level. They are reported in the publication ZIP ALERT, which is issued quarterly by the United States Postal Service[1] (www.ribbs.usps.gov/files/zipalert/).

Market Areas

Markets are both observed, empirically derived assessments of human commercial behavior and conceptualizations of an intended consumption or activity pattern. While markets are most often associated with the buying and selling of goods and services in a commercial sense, markets can also be applied to activity spaces that describe general behavior. In the health sector, a hospital's market area may reflect where its patients come from, but also the people it reaches in information dissemination and prevention programs acting through intermediary agents.

Markets are defined at varying levels of geography:

- for local goods and services. For example, these can take the form of a neighborhood bounded by streets or roads, collections of ZIP codes, or a city and its surrounding area.

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[1] The Census Bureau maintains a Master Area Block Level Equivalency file (MABLE) that crosslists ZIP codes with the census boundary files. Using that crosswalk, the census reports data at the ZIP code level on "Summary Tape File-3" (STF-3). The ZIP codes included on that file are modified in that they are the ZIP codes that have some boundary characteristics. They include within those boundaries the ZIP codes that are assigned, for example, to a post office and its related boxes or to a "point" ZIP that is a building or institution.

- for regional markets. These are usually described in terms of a set of counties or a region of a state or states. Examples include central Missouri and the Delmarva Peninsula.
- for national and global markets.

There are theories or generalizations about markets and market areas that may apply to the questions at hand. Health as a function of lifestyle, diet, and exercise may be considered exclusively within an individual's control, but the ability to exercise and the diet choices available to a person are tied to his or her lived space. The forces that shape those choices are, in turn, influenced by national trends and policies. They are also influenced by the structure of health care delivery systems related to a higher order market befitting a complex, technology-associated service industry. Health promoting or shaping goods and services are usually "produced" in central places where local economies can support the people and systems necessary to produce those services and goods.

Even the development of data that might identify local disparities depends on geographically large market areas. Epidemiological and statistical analysis and interpretation is efficiently done for markets that are centered on the larger state health departments and research universities. Nationally, a market might be made up of perhaps 100 centers that "sell" or provide these services. The idea of devolving this process of statistical abstraction to localities may not adequately consider the realities of these market structures.

There are a number of potential general market-derived geographies that are candidates for assessment of disparities in health. These include Labor Market Areas (LMAs)[2] and ZIP code clusters.

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[2] LMAs are formally described using county-level data and are based on a clustering algorithm that makes use of county-to-county commuting flows that are part of the census data collection process. The basic clusters of counties that are used to develop labor market areas are called commuting zones (CZs). In 1990, 741 commuting zones were delineated for all U.S. counties and county equivalents. These commuting zones are intended to represent more local labor markets. They are then aggregated into 394 Labor Market Areas (LMAs) by the Bureau of the Census, which uses a population

Currently, there are 394 multi-county LMAs in the U.S. that are constructed from 741 multi-county "commuting zones," which are defined using census data. Labor Market Areas are generally considered too large for meaningful local or community interventions.

5–4. TECHNICAL ISSUES

The complex considerations associated with formulating and applying geographic units to health care policy necessarily involve important technical issues. The following presents an overview of data and localities, technical problems with community indicators, and GIS.

Data and Localities

In describing localities, data are often drawn from systems that use the county as the denominator for a population rate or the state as the sampling frame for a survey. The problems of applying data from multiple levels of aggregation to analyze conceptually coherent neighborhoods or communities in the U.S. have been described in several places (Diez-Roux, 1998; Duncan et al., 1998). The analytical difficulties inherent in this type of statistical work can create an "ecological fallacy," which attributes collective characteristics to very dissimilar individuals. They can also reflect a lack of agreement on the power and specificity of multi-level modeling.

The geographic unit of analysis is often key to the ability of a measure to be sensitive to the underlying construct or local characteristic that is being measured. In a review of studies of geographic access to health care in rural areas, Connor and colleagues described studies that used "town/community/ZIP code areas," counties, "market share defined areas," and "other areas," which were usually aggregates of ZIP codes or clusters of counties (Conner et al., 1994). They were seeking guidance on the appropriate unit of analysis

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threshold of 100,000 for the LMA designation. In health care policy LMAs are used for the calculation of certain inputs to payment systems for the Centers for Medicare and Medicaid Services (CMS) and have been used in the analysis of the ability of rural areas to recruit physicians (Brasure et al., 1999).

for assessments of the adequacy of access and guidance for allocating resources. The review did not support the idea of access as a unifying concept that would lead to a consensus definition of an appropriate geographic unit. The general geographic size of places where access was most effectively measured was at the local level, usually consisting of small counties or clusters of ZIP areas. It was closely associated with the system that was meant to affect or provide access to primary care. In these areas, the fit between a measurable disparity in access closely approximated the area in which a solution could be achieved either through the enhancement of availability (for example, creating a clinic) or modifying some factor that reduced access (for example, developing a subsidy for care). However, many of the studies they reviewed made note of, but seldom measured, important effects and influences on the programs and projects from adjacent areas or state systems.

Technical Problems with Community Indicators

The determination of small area rates and indices describing the health status and health care resources available to populations is subject to varying degrees of error. In creating these rates and indicators, analysts rely on a largely dispersed and cooperative system of reporting that is based on local and state rules and laws, although the standards and guidelines are centrally agreed upon. Mortality rates, overall, are generally considered accurate, but there is evidence that cause of death is often miscoded on death certificates that are the source of mortality data (Kircher, 1985; Goodman and Berkelman, 1987). The accuracy of health care resource data is not often called into question, but for secondary data analysis there are problems with national data sources that may skew a picture of a county or community. The American Medical Association (AMA) Masterfile is the most frequently used source for national estimates of physician supply down to the county level, but it has been shown to have a degree of error due to reporting lags and the high mobility of physicians (Cherkin and Lawrence, 1977; Grumbach et al., 1995; Williams et al., 1996). For rural areas, the difference between the number of physicians reported in the Masterfile and the actual, locally verified number is striking in many places (Konrad et al., 2000; Ricketts et al., 2000). At the state level, license and survey data indicate that the Masterfile may overestimate primary care physician supply by as much as 20 percent. Data for nurses, pharmacists, and other health professionals are far less accurate when drawn from national sources because of the lack of a national inventory system (Kresiberg et al., 1976; Osterweis et al., 1996).

Geographic Information Systems as Savior?

GIS has been proposed by some as an all-purpose answer to problems of community characterization. It is touted as capable of solving resource allocation problems as well as of being an essential part of the field epidemiologist's armamentarium. The widespread use of GIS in public health came relatively late in the development of computer-assisted cartography and geographic analysis largely due to the lack of useful data to attach to geographic coordinates (Rushton et al., 2000).[3] *Healthy People 2010* includes the goal of increasing "the proportion of all major national, State, and local health data systems that use geocoding to promote nationwide use of geographic information systems (GIS) at all levels" from a baseline of 45 percent to 90 percent (Office of Disease Prevention and Health Promotion, 2001, pp. B23–4).

Geographic information systems carry the strong promise of a new, liberating technology and are often advertised to have the capacity to allow complex information to be displayed clearly and transparently, making both problems and solutions apparent. However, GIS is not really a new technology, but an expansion and intensification of older technologies. The expansion of the use and capacity of computers has facilitated collection of data by using remote sensing or by tapping into administrative, statistical, or clinical datasets. However, the massive amount of data that is now available has not immediately led to marked improvements in health care, the identification of health problems, or the formulation of health solutions because the volume of data has outpaced our ability to understand it.

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[3] However, some of the first applications of automated cartography were used to address health services problems.

GIS, however, has renewed interest in the use of spatial data as well as of statistical data of all types to explore questions, and to conduct surveillance of health systems and communities. The power of a map or data displayed in reference to space cannot be underestimated. The ability to quickly depict data in maps and graphs using GIS has made many problems seem more tractable because they can be understood in a context that is shared by analysts, policy makers, and stakeholders. At the same time, the classical errors of the mapmaker are repeated, and the ability to "lie with maps" is increasingly recognized as a threat to the validity of analysis on the order of more standard statistical misapplications (Monmonier, 1991).

5–5. CONCLUSION

Geographers who examine the relationship between place and health believe that it is formed less by the intrinsic nature of fixed places than by how people interact across space to make a particular place more or less healthy. The relationship between HIV infection and interstate highway locations represents a perfect example of a health consequence that is literally in motion and dependent upon place only to facilitate transmission. The consequences are felt at a distance. Injury prevalence is dependent on risks that are tied to geography: higher rates of trauma in rural areas are due to factors related to exposure and behavior (snowmobile use, chainsaws, tractors, higher highway speeds, lower seatbelt use) that reflect the interaction between human activity and space and places. These are disparities in risks are related to geography. Paradoxically, urban places tend to be a bit safer in terms of trauma. There are more guns in rural places, and firearm injury rates are higher. Also, the urban-rural differential in drug and substance abuse is no longer so great as to create clear contrasts in the net health effects of crime. There are obvious structural and physical differences between the decaying inner city of Scranton, Pennsylvania and of the "cotton trail" area of South Carolina. However, the health disparities in access, services, and quality are fundamentally the same and described in the same terms. Across geographies there is a convergence of human health status and of how we deal with it.

While geographic location is associated with wide variations in access, health care use, and health status, two core geographic elements and their relationship to health disparities are not well understood. They are distance (time and topography fit under this heading as well) and weather. Measuring distance often involves the use of rough estimations that mask actual geographic patterns of use. In many studies of the effects of distance, populations are described by some geographic entity such as a ZIP code or county, and the "average" distance to some location of care using the center of the geographic unit is calculated. This means that the variation or disparity due to differences in distance that exist within this geographic unit is lost to the analysis. The option is then to examine the relationship between an individual's distance to care and health status or outcomes. The latter analytical approach is feasible, but the former is far less expensive. Much of what we know about the effects of distance on health is based on the former type of studies. The degree to which true effects of distance are missed by this ecological approach is not well understood. Similarly, analysts and researchers often ignore differences in weather and environment and their effects on access, especially in the United States. We are constrained by our boundaries in such a way that we may not be able to completely understand how geography does affect disparities.

The relationship of neighborhood residence to health may be considered a form of pure geographic effect since neighborhoods are a combination of topography and social interaction. However, a reliable definition of neighborhood is elusive, and bringing some form of consistency to its measurement may be antithetical to a concept that strives to reflect the variety of human interaction. Measuring true geographic disparity has been difficult, and summary approaches that compare populations often mask evidence of disparity. We may have to begin to think of geography in the study of health disparities as more of an individual characteristic as opposed to a way to organize population analysis.

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APPENDIX I

WORKSHOP AGENDA

IOM Committee for Guidance in Designing
A National Healthcare Disparities Report[1]
March 19–20, 2002
Washington, DC, Green Building, 2000 Wisconsin Ave., NW

Day 1: Presentation and Discussion of Commissioned Papers

9:30–9:45 am	**Welcome** Sheldon Greenfield, M.D. (Chair, IOM Committee for Guidance in Designing a National Healthcare Disparities Report)
9:45–10:00 am	**Bias and Conflict of Interest Statements (Closed)** Janet Corrigan, Ph.D. (IOM)
10:00–10:20 am	**The Importance of Health Care Disparities and the National Healthcare Disparities Report** Helen Burstin, M.D., M.P.H. (Agency for Healthcare Research and Quality)

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[1] Meeting agendas, commissioned papers, written testimony, and other material can be found on the committee's public website: www.iom.edu/healthcaredisparities.

10:20–11:05 am	**Study: Subnational Data Sources** Author: Ross Arnett (Independent Consultant) Discussants: Eileen Peterson, M.S.P.H., and David Takeuchi, Ph.D. (IOM Committee Members)
11:05–11:10 am	**Break**
11:10–12:30 pm	**Study: SES and Health Care Disparities** Author: Marian Gornick, M.A. (Independent Consultant) Discussants: Kevin Fiscella, M.D., M.P.H., and Michael Marmot, Ph.D., M.P.H., F.R.C.P.
12:30–1:15 pm	**Lunch**
1:15–2:25 pm	**Study: Measuring Health Care Disparities in Access** Author: Nicole Lurie, M.D., M.S.P.H. (RAND) Discussants: John Ayanian, M.D., M.P.P., and Marsha Lillie-Blanton, D.P.H. (IOM Committee Members)
2:25–2:30 pm	**Break**
2:30–3:30 pm	**Study: Geographic Disparities** Author: Thomas Ricketts, Ph.D., M.P.H. (UNC-Chapel Hill) Discussants: James Bernstein, M.H.A., and E. Richard Brown, Ph.D. (IOM Committee Members)
3:30–3:45 pm	**Break**
3:45–5:00 pm	**Commissioned Paper: Disparities in Health Care Services and Quality** Author: Thomas LaVeist, Ph.D. (Johns Hopkins University) Discussants: Joseph Betancourt, M.D., M.P.H., and Neil Powe, M.D., M.P.H., M.B.A. (IOM Committee Members)

5:00–5:05 pm	**Closing Remarks** Sheldon Greenfield, M.D. (Chair, IOM Committee for Guidance in Designing a National Healthcare Disparities Report)
5:00–5:15 pm	**Break**
5:15–8:00 pm	**Committee Session/Working Dinner (Closed)**
8:00 pm	**Adjourn**
Day 2: Public Comment Sessions	
8:25–8:35 am	**Welcome** Sheldon Greenfield, M.D. (Chair, IOM Committee for Guidance in Designing a National Healthcare Disparities Report)
8:40–9:45 am	**Public Health** Ulder Tillman, M.D., M.P.H. (Association of State and Territorial Health Officials) Vanessa Northington Gamble, M.D., Ph.D. (Health Policy and Medical Education Consultant) Keith Mueller, Ph.D. (University of Nebraska) Adewale Troutman, M.D., M.P.H. (National Association of County and City Health Officials) Steven Wilhide, M.P.H., M.S.W. (National Rural Health Association)
9:45–9:55 am	**Break**
9:55–11:10 am	**Health Care Purchasing and Providing** Kathryn Coltin, M.P.H. (American Association of Health Plans) Dennis Andrulis, Ph.D., M.P.H. (SUNY) David Nerenz, Ph.D. (Michigan State University) Rea Panares, M.H.S., and Julianna Gonen, Ph.D. (Washington Business Group on Health)

11:10–11:20 am	**Break**
11:20–12:20pm	**Health Care Delivery**
	Juan E.Carillo, M.D., M.P.H. (New York Presbyterian)
	Merle Cunningham, M.D., M.P.H. (Lutheran Medical Center, Brooklyn, NY)
	Gina Gregory-Burns, M.D. (Kaiser Permanente)
	Arthur Elster, M.D. (American Medical Association)
12:20–1:15 pm	**Working Lunch**
1:15–2:15 pm	**General Comments on the National Health Care Disparities Report**
	Roger Bulger, M.D. (Association of Academic Health Centers)
	Gem Daus, M.A. (Asian and Pacific Islander American Health Forum)
	Andrew Imparato, J.D. (American Association of People with Disabilities)
	Bette Keltner, Ph.D., R.N., F.A.A.N. (American Nurses Association)
	Darlene Nipper, M.S. (National Alliance for the Mentally Ill)
	Lucille Perez, M.D. (National Medical Association)
	Jeanette South-Paul, M.D. (American Academy of Family Physicians)
2:15–2:30 pm	**Closing Comments**
	Sheldon Greenfield, M.D. (Chair, IOM Committee for Guidance in Designing a National Healthcare Disparities Report)

APPENDIX II

PUBLIC TESTIMONY

The committee devoted a day of its two-day March workshop to hearing testimony on the National Healthcare Disparities Report from 20 academics, advocates, and other national experts on racial, ethnic, geographic, and socioeconomic health care disparities. Table II–1 presents the names and organizational affiliations of those who appeared. The committee invited these experts after soliciting suggestions from a number of sources, including AHRQ. Committee members Joseph Betancourt and Doriane Miller planned the public testimony sessions.

Much of the testimony addressed two major issues:

1. Nature of the report. Many of the experts called for AHRQ to produce a report that would help policy makers, advocates, health care professionals, and others to better understand the causes behind disparities. A descriptive report, they believed, would document the kinds of disparities that are already well known. However, they believed that a report that also examined the factors that produce disparities could provide the basis for legislation and other kinds of policy change aimed at eliminating disparities. It could also serve as a means to monitor progress made towards elimination. In addition, it could provide an agenda for professional education, quality improvement initiatives, and further disparities-oriented research.
2. Analysis of Disparities. Experts offered their views on how the NHDR should analyze health care disparities. Many called for the report to take into account health care as well as the physical, social, and economic factors that affect health status and care. These factors include educational quality, health and social services, community crime rates, housing quality, and insurance barriers. Some experts identified certain kinds of disparity issues that should be included in the report such as those involving priority and chronic conditions and the languages spoken by patients and providers.

TABLE II–1 Expert Testimony on the National Healthcare Disparities Report

EXPERT	**ORGANIZATION**
Dennis Andrulis, Ph.D., M.P.H.	State University of New York Health Sciences Center
Roger J.Bulger, M.D., F.A.C.P.	Association of Academic Health Centers
Kathryn J.Coltin, M.P.H.	American Association of Health Plans
Merle Cunningham, M.D., M.P.H	Sunset Park Family Health Center Network of Lutheran Medical Center
Gem P.Daus, M.A.	Asian and Pacific Islander American Health Forum
Arthur B.Elster, M.D.	American Medical Association
Vanessa Northington Gamble, M.D., Ph.D.	Health Policy and Medical Education Consultant
Julianna Gonen, Ph.D.	Washington Business Group on Health
Gina Gregory-Burns, M.D.	Kaiser Permanente
Andrew J.Imparato, J.D.	American Association of People with Disabilities
Bette Keltner, Ph.D., R.N., F.A.A.N.	American Nurses Association
Keith Mueller, Ph.D.	Nebraska Center for Rural Health Research, University of Nebraska
David Nerenz, Ph.D.	Institute for Health Care Studies, Michigan State University
Darlene Nipper, M.S.	National Association for the Mentally Ill
Rea Pañares, M.H.S.	Washington Business Group on Health
Lucille Norville Perez, M.D.	National Medical Association
Jeannette South-Paul, M.D.	American Association of Family Physicians
Ulder Tillman, M.D., M.P.H.	Association of State and Territorial Health Officials
Adewale Troutman, M.D., M.P.H.	National Association of City and County Health Officials
Steven Wilhide, M.P.H., M.S.W.	National Rural Health Association

In addition, experts raised data-related issues such as the need to collect accurate data on insurance coverage, including provider and payment systems. This would avoid reliance on inaccurate recall by survey respondents. Data from health care plans on racial and ethnic identification could also be improved by, for example, coordinating the data that health care plans must gather, risk adjusting for disparity reporting, and formulating and disseminating interventions to eliminate disparities.

Experts raised other analytical issues. They include the following:

- The report should present information on disparities that can inform health care policy at the federal, state, and local levels.
- The report should permit data on health care disparities to be tracked over time.
- The report should contain data that are especially pertinent to some races or ethnicities such as nativity and language proficiency.
- The report should recognize the diversity of geographic areas. For example, some rural areas are closer to major metropolitan areas than others and some suburban areas have substantial racial and ethnic populations.

The report should use levels of analysis that include individuals, communities, and health care systems.

APPENDIX III

COMMITTEE BIOGRAPHIES

Sheldon Greenfield, M.D. (Chair)

Sheldon Greenfield is the Director of the Primary Care Outcomes Research Institute at Tufts University School of Medicine, Professor of Medicine and Community Medicine at Tufts University School of Medicine, and Adjunct Professor of Public Health, Harvard School of Public Health. He is an internist, having completed his residency at the Beth Israel Hospital in Boston where he began to work on clinical algorithms for nurse practitioners in the early 70's. He has pioneered research in increasing patients' participation in care and using outcomes to determine the value of that participation. He was Medical Director of the Medical Outcome Study (MOS), which sought to compare systems of care, specialties, various aspects of interpersonal care and resource use to outcome. He was Principal Investigator of the Type II Diabetes Patient Outcome Research Team (PORT). He was Co-director of the RAND-UCLA Center for Health Policy Study. He is former President of the Society of General Internal Medicine and was Chairman of the Health Care Technology Study Section for the Agency for Health Care Policy and Research. He was the 1995 recipient of the PEW Health Professions Commission Award for lifetime achievement in Primary Care Research. In 1997, he received the Glaser Award of the Society for General Internal Medicine. He is a member of the Institute of Medicine. He is Chairman of the Diabetes Quality Improvement Program, a joint venture of the Centers for Medicare and Medicaid Services, the National Committee for Quality Assurance, and the American Diabetes Association (ADA). He has been appointed Chair of the Provider Recognition Committee for the ADA, and is the 1999 recipient of the Novartis Global Outcomes Leadership Award of the International Society for Pharmacoeconomic Research. He was a member of the Institute of Medicine Committee on the National Quality Report on Health Care Delivery.

Lu Ann Aday, Ph.D.

Lu Ann Aday, Ph.D., is Lorne Bain Distinguished Professor in Public Health and Medicine at the University of Texas School of Public Health. She received her doctorate in sociology from Purdue University, and was formerly Associate Director for Research at the Center for Health Administration Studies of the University of Chicago. Dr. Aday's principal research interests have focused on indicators and correlates of health services utilization and access. She has conducted major national and community surveys and evaluations of national demonstrations and published extensively in this area, including thirteen books dealing with conceptual or empirical aspects of research on access to health and health care for vulnerable populations. Her most recent books—all of which have been published in second editions—include *At Risk in America: The Health and Health Care Needs of Vulnerable Populations in the United States* (Jossey-Bass, 1st ed., 1993; 2nd ed., 2001); *Designing and Conducting Health Surveys: A Comprehensive Guide* (Jossey-Bass, 1st ed., 1989; 2nd ed., 1996); and *Evaluating the Healthcare System: Effectiveness, Efficiency, and Equity* (Health Administration Press, 1st ed., 1993; 2nd ed., 1998). She received the University of Texas at Houston Health Science Center Excellence in Scholarship Award; John P.McGovern Outstanding Teacher Award; Committee on the Status of Women Distinguished Professional Woman Award; and the Minnie Stevens Piper Foundation Award for Excellence in Teaching. Dr. Aday is a Member of the Institute of Medicine of the National Academy of Sciences.

John Z.Ayanian, M.D., M.P.P.

Dr. Ayanian is an Associate Professor of Medicine and Health Care Policy at Harvard Medical School and Brigham and Women's Hospital, where he practices general internal medicine. His research focuses on quality of care and access to care for major medical conditions, including colorectal cancer and myocardial infarction. He has extensive experience in the use of cancer registries to assess outcomes and evaluate the quality of cancer care. In addition, he has studied the effects of race and gender on access to kidney transplants and on quality of care for other medical conditions. Dr. Ayanian is Deputy Editor of the journal *Medical Care,* a Robert Wood Johnson

Foundation Generalist Physician Faculty Scholar, and a Fellow of the American College of Physicians. He is currently a member of the Institute of Medicine Committee on the Consequences of Uninsurance.

James Bernstein, M.H.A.

Currently serving as the Assistant Secretary for Health, Mr. Bernstein oversees the North Carolina Departments of Facility Services, Medical Assistance, Mental Health, Minority Health, Public Health, and Rural Health. In 1973, Mr. Bernstein founded the nation's first Office of Rural Health, which has become the model for the nation in helping rural communities develop their own health care systems. Now known as the Office of Research, Demonstrations, and Rural Health Development, Mr. Bernstein's agency has further expanded its work and serves as the research and development arm of the N.C. Department of Health and Human Services. The Office is the lead agency for nine Medicaid managed care demonstrations covering 230,000 patients. In 1982, Mr. Bernstein founded the N.C. Foundation for Advanced Health Programs, a non-profit solely supported by private grant funding to carry out wide-ranging projects on health care delivery. Serving as its first and only President, he has secured private grant funding for a variety of projects, ranging from school health to pharmacy assistance for indigents to cost-effective health care delivery. Mr. Bernstein has served as President of the National Rural Health Association, and for six years as a member of the Prospective Payment Assessment Commission. He also has served on the Board of Directors of the Winthrop Rockefeller Foundation; and as program director of Practice Sights: State Primary Care Development Strategies, a Robert Wood Johnson Foundation national program. He is a Senior Research Fellow with the Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.

Joseph Betancourt, M.D., M.P.H.

Joseph Betancourt's primary interests include cross-cultural medicine, minority recruitment into the health professions, and minority health/health policy research. As a member of the Institute for Health Policy and Program Director for Multicultural Education at Massachusetts General Hospital (MGH), Dr. Betancourt's research has focused on: 1) correlating domains of cross-cultural communication and interpersonal processes of care in minority populations to adherence, utilization and outcomes; 2) developing a framework for cultural competence as both a health policy initiative and quality measure; and 3) exploring root causes for racial/ethnic disparities in heath. He is currently a Principal Investigator on a grant from the Centers for Medicare and Medicaid Services (CMS) entitled "Hispanic Health Services Utilization: Defining and Exploring Disparities" and on a grant from the Commonwealth Fund entitled "Cultural Competence in Health Care: A Practical Synthesis for Multilevel Policy Implementation." He is also Co-investigator on a National Cancer Institute grant entitled "Understanding Racial Differences in Lung Cancer Treatment." Dr. Betancourt is a member of the Institute of Medicine's Committee on Understanding and Eliminating Racial/Ethnic Disparities in Health Care. He is the author of several publications, co-editor of the special issue of *Patient Care* on eliminating racial and ethnic disparities in health, and a co-author of a paper published in *Annals of Internal Medicine* entitled "Cross-Cultural Primary Care: A Patient-Based Approach." Dr. Betancourt received his Bachelor of Science from the University of Maryland, his medical degree from the UMDNJ-New Jersey Medical School, and completed his residency in Internal Medicine at the New York Hospital-Cornell Medical Center. Following residency, he completed The Commonwealth Fund-Harvard University Fellowship in Minority Health Policy, and received his master's degree in public health from the Harvard School of Public Health. He served as Associate Director of the Center for Multicultural and Minority Health at New York Presbyterian Hospital-Weill Medical College of Cornell University before returning to Harvard.

E.Richard Brown, Ph.D.

Richard Brown is Professor of Community Health Sciences and Health Services in the UCLA School of Public Health and is the Director of the UCLA Center for Health Policy Research. He received his Ph.D. in sociology of education from the University of California-Berkeley. Dr. Brown has studied and written extensively about a broad range of issues and policies that affect the access of disadvantaged populations to health care. His recent research focuses on health insurance coverage, the lack of coverage, and the effects of public policies, managed care, and market conditions on access to health services, particularly for disadvantaged populations, Latinos and other racial and ethnic groups, and immigrants.

Dr. Brown is the principal investigator for the new California Health Interview Survey (CHIS), one of the nation's largest ongoing health surveys, which is specially designed to be inclusive of California's ethnic and racial diversity. CHIS covers a broad range of health issues, including health status and conditions, a broad array of public health issues, and health insurance and access to care. CHIS results are disseminated to a very wide and diverse set of constituencies. Dr. Brown previously led a UCLA research team that pioneered the adaptation of the National Health Interview Survey to develop state-level estimates of health status and conditions, health care access, and the use of services.

He also has been extensively involved in the analysis and development of public policies, with particular emphasis on health care reform. He served as a full-time senior consultant to the President's Task Force on National Health Care Reform, for which he co-chaired the work group on coverage for low-income families and individuals. He also has served as health policy adviser to two members of the United States Senate and several candidates for President.

Dr. Brown has served on several National Academy of Science study committees, including the Committee on the Prevention and Control of Sexually Transmitted Diseases and the Committee on the Health and Adjustment of Immigrant Children and Families. He is a past President of the American Public Health Association.

Kevin Fiscella, M.D., M.P.H.

Kevin Fiscella is an Associate Professor in the Departments of Family Medicine and Community and Preventive Medicine, University of Rochester School of Medicine and Dentistry. He is a practicing family physician and serves as Co-director of Community Medicine in the Department of Family Medicine, HIV clinical coordinator at a federally qualified community health center, and medical director of a methadone maintenance program.

His research focuses on disparities in health and health care quality related to socio-economic status (SES), race, and ethnicity. He recently completed a study supported by the Robert Wood Johnson Foundation and the Health Care Financing Organization that compared socioeconomic disparities in health care in HMOs with those in indemnity plans. He also recently completed a report for the National Quality Forum, entitled, "Using Existing Measures to Monitor Minority Health Care Quality." He is currently working on a project funded by the Agency for Healthcare Research and Quality (AHRQ) that examines the impact of adjustment for patient SES on physician practice profiles and is preparing a report for AHRQ on state-of-the-art quality measurement for minority and vulnerable populations.

Marsha Lillie-Blanton, D.P.H.

Marsha Lillie-Blanton is a vice-president of the Henry J. Kaiser Family Foundation, where she directs policy research on access to care for vulnerable populations. Prior to joining the foundation, Dr. Lillie-Blanton served as Associate Director of Health Services Quality and Public Health Issues at the U.S. General Accounting Office. Dr. Lillie-Blanton has over fifteen years of work experience in health policy research and management positions, including serving formerly as Associate Director of the Kaiser Commission on the Future of Medicaid. From 1990–94, Dr. Lillie-Blanton was an assistant professor of health policy and management at the Johns Hopkins University School of Public Health. She currently holds an adjunct faculty position in the School of Public Health, and her primary research interests are in the areas of substance abuse, HIV/AIDS, and minority health. She has authored and co-authored numerous reports and publications. Her efforts in directing the work of eight teams of researchers analyzing data from the National Medical Expenditure Survey resulted in the publication *Achieving Equitable Access: Studies of Health Care Issues Affecting Hispanics and African Americans.* Dr. Lillie-Blanton is both a health policy researcher and a public health practitioner who is active in civic and local affairs. She currently serves as a member of the Medicaid Advisory Committee of the D.C.

Department of Health and the National Advisory Council for the Agency for Health Care Policy and Research. She is also an elected member of the National Academy of Social Insurance. Dr. Lillie-Blanton received a bachelor's degree from Howard University and a master's and doctoral degree from the Johns Hopkins University School of Public Health.

Michael Marmot, Ph.D., M.P.H., F.R.C.P.

Michael Marmot is Professor of Epidemiology and Public Health and Director of the International Centre for Health and Society (established in 1994) at University College London. He has previously held research posts at the University of California (Berkeley); the University of Sydney, Australia; and the London School of Hygiene & Tropical Medicine.

His research interests center on the epidemiology and prevention of cardiovascular disease, and the social and cultural determinants of disease, with a particular focus on psychosocial factors and nutrition. He is currently Principal Investigator of the Whitehall studies of British civil servants, and Principal Investigator of the newly launched English Longitudinal Study of Aging. Together with the National Centre for Social Research, the International Centre for Health and Society conducts the Health Surveys for England and Scotland. New research initiatives include investigating social gradients in health in the Japanese, investigating causes of East-West differences in coronary heart disease, and pursuing an initiative on psychological triggers of biological pathways of disease.

Professor Sir Michael was awarded an MRC Research Professorship in 1995. He was a member of the Chief Medical Officer's Committee on Medical Aspects of Food Policy and of the Chief Medical Officer's Working Group on "Our Healthier Nation"; a member of the MacArthur Foundation Network on Socio-Economic Status and Health; and a member of the Royal Commission on Environmental Pollution. He served on the Scientific Advisory Group of the Independent Inquiry into Health Inequalities chaired by Sir Donald Acheson, which reported in November 1998. He was knighted by HM The Queen in 2000.

Doriane C.Miller, M.D.

Doriane Miller joined the Robert Wood Johnson Foundation staff as program vice president in 1997. She brought the foundation 15 years' experience as a community-based primary care provider who had worked with underserved, minority populations with a special interest in mental health and substance abuse issues. She previously served as medical director of the Maxine Hall Health Center of the San Francisco Department of Health, while also serving as assistant clinical professor of medicine in the Department of Medicine at San Francisco General Hospital, University of California, San Francisco.

As a 1993 winner of an RWJF Community Health Leadership Award, she directed the Grandparents Who Care Support Group, which she co-founded in 1989. The program provides psychological help and community resources to relatives who are raising children because the children's' parents are mentally ill, incarcerated, or have substance abuse problems.

At the foundation, she heads the Clinical Care Management Team of the Health Care Group. She is responsible for coordinating strategies and funding in the area of clinical care management and quality improvement, and serves on the Board of Directors of Grantmakers in Health. Dr. Miller continues her professional practice by volunteering at the Chandler Clinic in New Brunswick, New Jersey, a community health center serving a low income, predominantly minority community.

Dr. Miller received her medical degree at the University of Chicago and completed her residency training at the University of California, San Francisco in primary care internal medicine.

Eileen H.Peterson, M.S.P.H.

Eileen Peterson oversees all research and evaluation functions for UnitedHealth Group's Center for Health Care Policy and Evaluation. She is responsible for a staff of research, analytic, and technical personnel engaged in the conduct of research projects in the areas of managed care effectiveness, quality of care evaluation and improvement, and clinical and cost effectiveness studies. In addition to her management responsibilities, she has an active research interest in methods for measurement and evaluation of quality in health care. Currently, she is the contract manager for the Integrated Delivery System Research Network or Rapid-Response Research Network, which is the new model of field-based research for the Agency for Healthcare Research and Quality (AHRQ). She is also the principal investigator of “Private Sector Data and Measures for the National Quality Report,” which is a response to a congressional request for a report that will begin to shed light more systematically on the quality of care delivered in the U.S.. Previously, she led development of the Center’s quality evaluation software, Quality Screening and Management (QSM), and the design of UnitedHealthcare’s medical management information system. Before joining the Center, she had experience both as a clinician and researcher, focusing on the areas of children’s health and chronic disease. She was involved with the conduct of clinical and population-based research at the University of Minnesota Medical School and the School of Public Health, and in the development of a research and analysis capacity at a large managed care health plan. She is an active consultant in the areas of managed care research and evaluation and serves as an advisor to AHRQ on its national research agenda. She has served on the advisory board for the National Policy Center for Children with Special Health Care Needs; and also is on the editorial board of Sage Publications for the book series, *Managed Care Research.* Eileen received bachelor’s degrees with highest distinction in both business and nursing, and a master of science in public health from the University of Minnesota.

Neil R.Powe, M.D., M.P.H., M.B.A

Neil R.Powe is Professor of Medicine at the Johns Hopkins University School of Medicine, Professor of Epidemiology and Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health, and Director of the Welch Center for Prevention, Epidemiology and Clinical Research, a research and training center at the Johns Hopkins Medical Institutions focused on clinical and population-based research. His research has involved clinical epidemiology, health services research and patient outcomes research using prospective methods of randomized controlled trials and cohort studies, cost-effectiveness analysis, meta-analysis, and retrospective analyses of administrative databases and survey research. Dr. Powe has published more than 170 articles.

Dr. Powe led the End-Stage Renal Disease Patient Outcomes Research Team and the ESRD Quality (EQUAL) Study. He has extensive experience in developing and measuring outcomes in chronic kidney disease. Dr. Powe has also studied racial differences in cardiovascular procedure use and kidney transplantation. Dr. Powe was a member of the IOM Committee on Measuring, Managing and Improving Quality of Care in the ESRD Treatment Setting. He has testified before the U.S. Congress on the role of patient outcomes research in improving the quality of care in the U.S. Medicare ESRD program and on how clinical evidence can be used in coverage decisions for new medical technology.

Dr. Powe trained in internal medicine and epidemiology, receiving his M.D. degree from Harvard Medical School, his M.P.H. degree from Harvard School of Public Health, and his M.B.A. degree from the University of Pennsylvania. He completed residency at the Hospital of the University of Pennsylvania, where he was also a Robert Wood Johnson Clinical Scholar and fellow in the Division of General Internal Medicine. Dr. Powe is a member of the American Society of Clinical Investigation and a Fellow of the American College of Physicians. He is the recipient of several national awards, including the best article of year (2000) by the Academy for Health Services Research and Health Policy. He was named one of the leading African-American physicians in the U.S. (2001) by Black Enterprise magazine.

David T.Takeuchi, Ph.D.

David T.Takeuchi is Professor and Associate Dean of Research in the School of Social Work at the University of Washington. He is a sociologist with postdoctoral training in epidemiology and health services research. His research focuses on investigating the social, structural, and cultural contexts that are associated with different health outcomes, especially among racial and ethnic minorities. He also examines the use of health services in different ethnic communities. He has published in a wide range of journals including the American Journal of Psychiatry, American Journal of Public Health, Archives of General Psychiatry, Contemporary Sociology, Journal of Community Psychology, Journal of Health and Social Behavior, Sociology of Education, and Social Forces. In addition to his scholarly work, he has assisted numerous community groups in conducting needs assessment and evaluation studies. He has written technical reports for community and state agencies on issues related to homelessness, discrimination confronting Hmong refugees and Filipino immigrants, multicultural education, Native Hawaiian health and mental health needs, and youth correctional programs.