



CHAPTER VII

DATA AND RESEARCH NEEDS

Many limitations of data collected and weaknesses in available research in women's health affected the *Report Card*, both in identifying potential indicators and in obtaining consistent state-by-state data. This section of the *Report Card* describes: (1) general issues related to the methods of collection, reporting and analysis

of data, and (2) issues related to the scope and breadth of research on specific areas of concern for women. This *Report Card* also notes changes in data and research since the release of the 2000 *Report Card*.¹

Overarching Gaps in Data and Research

Gaps in research and data collection limit the scope of biomedical and behavioral research on women, and prevent informed decision making about policies and resources that affect women. Since the 2000 *Report Card*, however, some improvements have been made.

- **More data are available by sex and other important factors, but significant gaps persist.** As noted throughout the *Report Card*, more state data are now available by sex and also by race/ethnicity and age. Since the 2000 *Report Card*, the federal National Center for Health Statistics, with support of the federal Office on Women's Health, has expanded readily available public data beyond mortality data (i.e., data about the causes of death) to also include morbidity (i.e., data about illness) and disease risk factor data by race/ethnicity and age.² The federally sponsored Behavioral Risk Factor Surveillance System (BRFSS) now provides state-level information on specific *Report Card* status indicators (including health insurance, most of the

wellness and prevention indicators, and several morbidity indicators).

Several other new efforts have enhanced the data available. A forthcoming *Chartbook on Women's Health* analyzes data by sex as it relates to access, health insurance and health status at the national level.³ Another federal survey examines women's utilization of health care by sex, race and ethnicity.⁴ The federal Agency for Healthcare Research and Quality (AHRQ) is preparing the first annual report on the quality of health care in the United States.⁵ Finally, the Maternal and Child Health Bureau's performance measurement work provides data from all states on indicators that include a number related to women's health as well as others that states select themselves. These state-selected indicators include those related to chlamydia, tobacco use, use of alcohol and other drugs by pregnant women and service-related indicators such as family planning, HIV counseling and testing, and domestic violence.⁶

However, state-level data analyzed by sex are still limited in at least two important ways. First, most national surveys that analyze data by sex often do not also analyze these data by state.⁷ Second, even those national efforts that offer data analyzed by state and sex do not include comparable data for all 50 states and the District of Columbia. For example, there are some states that do not participate fully in the CDC national survey efforts such as the Pregnancy Risk Assessment Monitoring System (PRAMS). In the case of PRAMS, considerable data related to maternal attitudes and experiences prior to, during, and immediately following pregnancy are available. However, PRAMS requires state financial support, with only 32 states participating, so its useful data cannot be used for the *Report Card's* state-by-state analysis.

Further, the BRFSS is limited by the degree to which states participate in those efforts.⁸ All 50 states and the District of Columbia participate in the BRFSS and the *Report Card* makes extensive use of BRFSS data where all states participate. There are, however, areas of inquiry in which states are not required to participate, and thus many do not, leaving the data incomplete. Requiring state participation in more areas could provide data on several key areas for which the *Report Card* includes national data but does not have state-by-state information (e.g., arthritis, violence, osteoporosis, and unintended pregnancies).

- ***States and regions are also initiating their own data collection efforts to address gaps in national sources.*** Where gaps persist in national sources, states and regions are initiating their own data collection efforts. For example, in 2001, the U.S. Department of Health and Human Services Region VIII Public Health Service expanded on its previous report on women's health⁹ by providing a women's and minority health database on CD-ROM.¹⁰ The CD-ROM contains considerable data on a range of indicators at both the state and county level, including *Report Card* indicators and others that require state-specific sources. Such efforts, while extremely worthwhile, cannot be used for effective state-by-state comparisons unless other regions take similar steps.
- ***While there is increased attention to issues of concern to women of color and to other specific populations of women, serious gaps persist in data available and the research focused on these groups.*** There appears to be very little improvement in data availability for specific populations of women. As discussed in more detail in chapter VI, data on women of color continue to be on the broader racial and ethnic categories, with little or no data on the many subgroups within the broad racial/ethnic groups, which often differ substantially from each other. In some cases, even data on the broader categories are overlooked. For example, an analysis of Healthy People 2010 objectives indicates that 157 of 434 population-based objectives and sub-objectives lack data on Hispanics.¹¹

Data analyzing other characteristics such as disability, sexual orientation, socioeconomic status, geography (rural) and homelessness continue to be unavailable. For example, disability research has resulted in a very wide range of estimates of those who are affected by physical, mental, emotional, or other disabilities. Indeed, no single disability concept is sufficient for all policy and program issues.¹² A fuller exploration of disability issues would require direct questions about many different types of disabilities and impairments, as well as the ability to pursue the activities of daily living. The Census Bureau's Survey of Income and Program Participation contains many items relating to disabilities, however it is not designed to generate state-level data.¹³

There are several new efforts to address these gaps. A new federal law will expand data collection on health disparities that affect minority and underserved populations.¹⁴ The federal Office of Research on Women's Health (ORWH) at the National Institutes of Health (NIH) and the Agency for Healthcare Research and Quality (AHRQ) are supporting research on disparities among diverse racial and ethnic populations. The ORWH has issued a *Strategic Plan to Address Health Disparities Among Diverse Populations of Women*, which addresses the health needs of women of all races and ethnic backgrounds in the United States.¹⁵ The National Institutes of Health has also issued a program announcement on lesbian health research.¹⁶ In addition, the Gay and Lesbian Medical Association, in conjunction with other groups, released the *Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health*. This report examines the Healthy People 2010 objectives as they relate to LGBT populations and the availability of data.¹⁷ The report identifies 29 specific objectives that include sexual orientation as one of the ways data are to be reported but indicate that almost no data are currently available. The report also indicates that there continue to be serious gaps in research that may help identify areas of health where sexual orientation is an issue. It is still too early to tell whether these promising new efforts will significantly improve data on these specific populations of women.

- ***Availability of information on the content of and support for programs serving women continues to be limited and inconsistently available, hampering the development of policy indicators.*** The efforts to develop policy indicators continue to be hampered by the lack of mechanisms for comparing programs and services across states. It is also extremely difficult to ascertain the state funding of certain programs, because federal, state, municipal and private funds are often combined to support the same programs, but no accounting of the funding by state is publicly available. State record keeping does not always clearly indicate which funding streams support which specific programs. These problems impede efforts to compare service content or quality. Comprehensive data are needed to determine how well states fund programs that provide services or support to specific populations of women.

- ***There are several important status and policy indicators, as well as demographic profiles, for which data were not updated for inclusion in this Report Card.*** With respect to status indicators, these include state-level indicators for access to abortion providers, maternal mortality rates and life expectancy. Also, three indicators where data are available only on a national basis are not updated: violence against women, unintended pregnancies and osteoporosis. The problem is even more severe with respect to data on policy indicators, which are often not collected on a regular basis. The 2000 *Report Card* gathered information from numerous sources about policies that demonstrate a state's commitment to protecting and improving women's health. There are, however, several indicators for which data were not updated by the 2000 *Report Card's* sources or any other reliable source before the 2001 *Report Card* went to press. These policies are: family and medical leave, linguistic access, exercise, Medicaid smoking cessation treatment coverage, osteoporosis public education programs, child support pass-through, percentage of income paid in state/local taxes, monitoring potentially environment-related diseases/conditions, and per capita urban resident spending on public transportation. Also not updated are two demographic indicators: women living in linguistic isolation and births attended by a midwife.
- ***While participation of women in clinical trials has improved, more needs to be done to improve the participation of minority women and to use data from these trials more effectively to identify potential sex differences.*** The need to focus on addressing sex-specific research issues is reinforced by the release of an Institute of Medicine report, *Exploring the Biological Contributions to Human Health: Does Sex Matter?*¹⁸ The IOM report asserts that sex does make a difference in areas such as responses to drugs, perception of pain and how the brain functions. These differences therefore are critical considerations in designing research studies and in the analysis of data. Among the recommendations made by the IOM are that: sex be included as a variable in basic research designs; studies be encouraged at different stages of the life span; sex differences and similarities be monitored for all human diseases that affect both sexes; and that sex-specific data be made more available.

Significant efforts by the NIH's ORWH continue to support the recruiting of women into clinical trials and research specifically focused on women's issues. NIH continues to examine the cultural, structural, and linguistic issues affecting the participation of a broad range of women in clinical trials. The ORWH has taken the lead to ensure implementation of NIH's policies on the inclusion of women in research and convenes a NIH-wide Tracking Committee to monitor women's and minorities' participation in NIH-supported research.¹⁹ While progress has been made in ensuring that the inclusion of women and minorities in NIH-funded research (clinical research), there continues to be concern about whether drug development trials conducted and financed by private industry also include significant numbers of women and minorities.

A federal General Accounting Office (GAO) Report on FDA activities released in July 2001 found that women are now significantly represented among clinical trial participants in new drug applications, with sufficient participation to examine the effectiveness of these particular drugs for women.²⁰ However, women's increased participation in clinical trials has not completely addressed a number of key issues. These include the appropriate dosages of various drugs for women, how dosages might be affected by age and health status, and related safety issues. Low participation of women in critical phases of clinical trials when safety and dosage are determined continues to be a major problem in optimizing treatments for women.²¹

- ***Changes in available data, standards, and the shift to Healthy People 2010 provides challenges for selected Report Card indicators.*** Access to data has improved as a result of many data sets being placed on the Internet (for example, by the National Center for Health Statistics). Healthy People 2010, including the 2010 Leading Health Indicators, provides new benchmarks for a variety of important women's health measures.²² Of the 467 population objectives, breakouts by sex are planned for 336.²³ It is not clear whether data by sex are available for all of the 336 objectives. This will be an issue for researchers and policy makers affecting the ability to compare data over time including the ability to develop and analyze trends.²⁴

Specific Data and Research Gaps

The following discussion reviews changes as well as continuing issues in the specific indicators highlighted in the 2000 *Report Card*.

Women's Access to Health Care Services

Access to care is crucial to women's health and well-being. A variety of different approaches are required to measure adequately its multiple dimensions. Gaps in the data and the limits on

research that impede assessment of women's access to care are identified below.

- ***The lack of adequate information at the state level persists.*** There are still no reliable data on the number of women who are eligible for publicly funded health insurance programs but are not participating. Information on the range of barriers (such as transportation, child care, linguistic and cultural barriers, or immigrant status) and/or investments to reduce barriers that

keep women from either enrolling in programs or securing services is still not systematically collected. Little is known regarding the effects of underinsurance that may lead to late access and late diagnosis. Finally, data related to such issues as access and utilization of preventive services are lacking.

- **Limited new efforts are underway to evaluate the “cultural competency and cultural proficiency” of health care services, including both physical and behavioral health.** Although there is a growing commitment to ensuring the “cultural competence” of health care services and delivery, few efforts or methods are widely used to assess the range and quality of these services. These gaps in research severely limit the understanding of the overall picture of access to health care for women of color, lesbians, the disabled, and women in general.
- **There continues to be a lack of data regarding state support to safety net providers.** In the 2000 report evaluating the nation’s safety net providers, the Institute of Medicine (IOM) identified the need for comprehensive safety net monitoring. The IOM suggested tracking several measures, including the providers’ financial stability and their ability to meet the health care needs of the uninsured and other vulnerable populations,²⁵ but it does not appear that significant tracking measures have been implemented.
- **There continues to be inadequate information on women’s access to long-term care.** There are major gaps in data and research on women and long-term care. Existing state-level data are limited, making it very difficult to evaluate the range of long-term care options, especially those that support women living in their homes. Analysts need to evaluate further: state-mandated nursing home staffing levels; state support for home and community-based care; state enforcement of federal and state nursing home standards; and state support for respite care.²⁶
- **Further research is still needed to examine the range of health professionals used by women including nurse midwives and nurse practitioners.** Research is needed into the utilization patterns for various professionals, how that affects access to care, and the impact on quality of care and health outcomes.
- **More research is being supported on how medical errors affect the quality of care.** Following the 1999 Institute of Medicine report on hospital medical errors, there has been considerable attention to improving patient safety.²⁷ Recently, AHRQ released a report reviewing a large number of patient safety practices and identifying a number of effective practices.²⁸ In addition, a series of requests for proposals on patient safety research have been funded by AHRQ to further explore the issues. The AHRQ national report on health quality mentioned earlier may also help identify continuing needs for research.

- **Research on complementary and alternative medicines has made some progress.** The federal government’s National Center for Complementary & Alternative Medicine (NCCAM) initiated an evaluation of various approaches and developed a partnership with AHRQ for the conduct of evidence-based work.²⁹ Co-sponsored work includes examination of acupuncture for back pain and depression during and after pregnancy, and alternative medicine approaches to hormone replacement therapy.³⁰ NCCAM is also working in the area of disparities to examine the prevalence of complementary and alternative medicine by different minority and underserved populations.³¹

Addressing Wellness and Prevention

Very little is known about women’s health behaviors. It is critical to identify behavior associated with wellness and examine the effectiveness of programs designed to change behaviors.³²

- **Data on the availability of programs supported by states, the efficacy of prevention and treatment programs and the impact of policies should be collected consistently.** There continues to be little data on state supported exercise, physical activity or nutrition programs. Although evaluating the effectiveness (in terms of cost and disease prevention) of programs intended to prevent illness or promote wellness is essential to making informed decisions about policies affecting women’s health, few ongoing efforts evaluate the value of programs that serve women. Similarly, there is a significant lack of research regarding approaches to facilitating healthy behavior (e.g., nutrition programs) and approaches to daily prevention activities (e.g., exercise habits) among women as discussed in greater detail in the chapter on women and cardiovascular health.
- **Data on drug and alcohol abuse need to be strengthened.** There continue to be data gaps concerning the incidence and prevalence of drug and alcohol abuse among women. The National Household Survey on Drug Abuse has been expanded from reporting only on a national and regional level to providing state-level data. However, sex specific data at the state-level are still not available.³³ There is also a lack of consensus concerning which indicators are best for measuring drug use and abuse. In addition, data are not available regarding the number of women who need substance abuse treatment, the number of women who use the available programs, or the effectiveness of existing programs at treating women. Although there are state-by-state data on the number of women admitted to treatment each year, these data are not helpful without information about the need for the services, retention and graduation rates, and recidivism rates.³⁴ Publications addressing state commitment to addressing substance abuse that were released after last year’s *Report Card* provide useful starting points.³⁵

Key Health Conditions, Diseases and Causes of Death

There are a variety of data and research limitations on the major health conditions, diseases, and causes of death for women.

- ***A changing research base prevents clear consensus around some approaches to measurement, treatment and appropriate programming or resources for some key health conditions.*** For some key health conditions that affect women, significant debate remains concerning the intensity of the problem, appropriate measures to describe accurately the scope of concern, and the most effective prevention or treatment measures. In some cases (e.g., the lack of a screening mechanism for ovarian cancer, the advisability of hormone replacement treatment for menopausal women and cholesterol guidelines), there is still disagreement in the scientific community about the most appropriate course of action. Nevertheless, recommendations and guidelines reflect improved knowledge and new research findings.
- ***Some morbidity data are now available by sex and other characteristics but not for all diseases and conditions.*** In some cases, data are available in particular states but are not consistently available across all states. For example, considerable cancer data are available in those states with tumor registries and through the SEER (Surveillance, Epidemiology, and End Results) Cancer Statistics Review.³⁶ These data are not available by sex on a state level.³⁷
- ***The lack of state-level data and the reliance on national data make it difficult to present an accurate picture of how many women have certain conditions and diseases and what the available screening and treatment programs for key health conditions, diseases and causes of death are within a state.*** For the *Report Card*, key indicator selection criteria included the magnitude of the problem and whether or not there were treatments or preventive measures to address that condition or disease. Because data for these criteria were unavailable in several important areas, they could not be covered. This list, first identified in the 2000 *Report Card*, therefore highlights a selected set of conditions, diseases and causes of death where important data were unavailable:

HIV: Reported data in all states measure people living with AIDS and not people living with HIV, the virus that causes AIDS. Only about half of the states report HIV data. Particularly now that newer medications help to prevent the progression of HIV to AIDS, using AIDS data alone to estimate the number of people living with HIV is not sufficient.

Osteoporosis: There are no consistent data collected at the state level on the number of women with osteoporosis, or who receive bone-density screening.

Arthritis: There are no consistent data collected at the state level on the number of women with arthritis. The BRFSS now includes questions related to arthritis but as of the 2000 survey, only 36 states include these questions.

Unintended Pregnancies: There are no state-by-state data on the percentage of pregnancies that are unintended, other than for those women participating in PRAMS. However, even data on unintended pregnancies from PRAMS is not optimal since it does not include all women; the survey respondents include only pregnant or recently pregnant women.

Mental Health: Although there are accepted definitions for specific conditions, research is needed to help establish nationally accepted definitions and clinical parameters for overall mental health. The *Report Card* indicator for mental health status is self-reported via the Behavior Risk Factor Surveillance System. There is no universally agreed upon risk assessment or clinical database at the national or state level for mental health status.

Violence Against Women: This area continues to receive considerable attention. Much of the focus has been on defining violence and developing consistent data across all the states. Recommendations on public health surveillance and research on violence against women were released late in 2000.³⁸ The recommendations call for state-level data, on-going surveillance and research into methodological issues to address the large disparities across national surveys. The Centers for Disease Control and Prevention, as the only place for specific research within the Department of Health and Human Services, continues to support various projects researching issues related to intimate partner violence and the effectiveness of various interventions. Other efforts by AHRQ have also funded comparative studies examining the effectiveness of intervention programs offered in health care settings. The National Institute of Mental Health (NIMH) is also supporting research designed to provide information on improving efforts to prevent and reduce the mental health consequences of domestic violence. Other research is supported by the Department of Justice. Finally, a newly established interdepartmental committee that includes the Department of Justice and various agencies within the Department of Health and Human Services is looking at gaps in current research in order to create a new coordinated research agenda on violence against women.

Asthma: States do not consistently collect population-based data about the incidence or prevalence of asthma, nor do they consistently analyze the data by gender or ethnicity. More investigation is also needed to identify factors that cause and worsen asthma. Hospital discharge data provide information on avoidable hospitalizations due to lack of timely treatment but are not available for all states.

Eating Disorders: There are no state-level data concerning eating disorders prevalence, incidence or the availability and use of treatment.

Ovarian Cancer: More research into ovarian cancer is needed, particularly research focused on developing accurate screening tools, precise diagnostic tools and non-toxic therapies.

Oral Health: The 2000 Surgeon General's report on oral health reports on specific women's oral health issues and calls for additional research to understand sex and gender implications.³⁹ The Surgeon General's report also documents the limitations and/or lack of national and state data for many oral and craniofacial diseases and conditions, particularly for various special populations, as well as the need for research to develop better indicators.⁴⁰ In light of this recent emphasis on the importance of oral health in overall health, state policies on oral health need to be further evaluated, although some current reports provide helpful starting points.⁴¹

Living in a Healthy Community

Women's homes, communities and work environments all affect their health. There are serious research gaps in each of these areas and an overall need for more sophisticated research that addresses the complex issues involved in examining these indicators. Several issues were identified last year that still have not been adequately addressed. These include data and research on discrimination against women, the impact of the environment on women's health, and occupational health.

In conclusion, there have been improvements in data availability and increased attention to needed research. However, these changes are still not sufficient to meet the large gap that exists. It continues to be important to: develop appropriate baselines and benchmarks, support coordination across agencies and interested parties, provide sustained support for the data collection and database management efforts, expand national data to the state and local levels, and improve the timeliness of data for performance measurement and accountability.

Chapter VII Notes

- ¹ For a discussion of data and research in the 2000 *Report Card*, see National Women's Law Center and others, *Making the Grade on Women's Health: A National and State-by-State Report Card* (Washington, D.C.: National Women's Law Center, 2000), 167-171.
- ² National Center for Health Statistics, *State Health Statistics by Sex and Race/Ethnicity* [Online]; Available: WWW URL: <http://www.cdc.gov/nchs/statestatsbysexrace.htm>, accessed 20 July 2001.
- ³ The *Chartbook on Women's Health* was developed by the Medical Expenditure Panel Survey (MEPS) program of the federal Agency for Healthcare Research and Quality (AHRQ) and will provide approximately 30 tables of data analyzed by sex as it relates to access, health insurance and health status at the national level. The data will be available by such socio-demographic characteristics for women as race/ethnicity, education, marital status, insurance coverage and employment. Indicators covered include: physical and mental health, functional and activity status, health insurance status, usual source of care and use of such preventive care as Pap smears, mammograms and complete physicals. B. L. Kass and others, *Disparities and Gender Gaps in Women's Health, 1996, MEPS Chartbook No. 8* (Rockville: Agency for Healthcare Research and Quality, forthcoming). Although the *Chartbook* was not finalized before the research for the 2001 *Report Card* was completed, it promises to be a valuable tool for future publications.
- ⁴ This survey examines numbers of visits, the reasons for visits, providers used, drugs prescribed and sources of payments. The analysis, by sex, race and ethnicity, begins to address some of the gaps identified in the first *Report Card*. The Office of Research on Women's Health (ORWH) priorities provide more specific areas for women's health research such as: prevention and wellness, chronic diseases, mental health, reproductive health, sexually transmissible diseases, cancer, care giving and health-related quality-of-life issues, and complementary and alternative medicines and dietary supplements. National Center for Health Statistics, *Utilization of Ambulatory Medical Care by Women: United States, 1997-98, Series Report 13, No. 149* (2001).
- ⁵ In 2001, AHRQ began preparing the first annual report on the quality of health care in the United States. With the Institute of Medicine, AHRQ will track and assess performance measures on 15 conditions. Discussion with Marcy Gross, Senior Advisor on Women's Health for the Agency for Healthcare Research and Quality (August 2001). Requirements and support for data collection may enhance the *Report Card* effort by making better and timelier data available. For more information on the upcoming report, see Agency for Healthcare Research and Quality, "AHRQ Leading Effort to Develop National Report on Health Care Quality," Press Release 3, November 2000 [Online]; Available: WWW URL: <http://www.ahrq.gov/news/press/pr2000/natreppr.htm>, accessed 17 October 2001.
- ⁶ The data reported by the states are publicly available at www.mchdata.net and additional information regarding this source is highlighted in Health Resources and Services Administration, Maternal and Child Health Bureau, *Title V Today*, Volume 3, Issue 1 (Winter 2001).
- ⁷ Centers for Disease Control and Prevention, *National Health and Nutrition Examination Survey: What's New with NHANES, 2001* (Washington, D.C.: Centers for Disease Control and Prevention, 2001) [Online]; Available: WWW URL: <http://www.cdc.gov/nchs/about/major/nhanes/whatsnew.htm>, accessed 9 October 2001.
- ⁸ Centers for Disease Control and Prevention, *Pregnancy Risk Assessment Monitoring System* (Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, August 2001) [Online]; Available: WWW URL: http://www.cdc.gov/nccdphp/drh/srv_prams.htm, accessed 9 October 2001; Centers for Disease Control and Prevention, *Behavioral Risk Factor Surveillance System* (Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, October 2001) [Online]; Available: WWW URL: <http://www.cdc.gov/nccdphp/brfss/>.
- ⁹ U.S. Department of Health and Human Services, Public Health Service, *Region VIII, Region VIII Women's Health Status Indicators* (Denver: U.S. Department of Health and Human Services, 1999).
- ¹⁰ U.S. Department of Health and Human Services, Public Health Service, Region VIII, *Women's and Minority Health Database* (Denver: U.S. Department of Health and Human Services, 2001). This CD-Rom contains a variety of data sources at the state and when available, county-level data.
- ¹¹ National Alliance for Hispanic Health, *Through Our Eyes: Creating a Healthy Future* (Washington, D.C.: Estrella Press, 2000), 21 (reasons identified for the lack of available data are: lack of analysis of available data (23); statistical unreliability (84) and data not collected (50)). The organization's website is: <http://www.hispanichealth.org/toe.htm>, accessed 10 October 2001.
- ¹² For example, the primary focus of the Current Population Survey is on the labor force, with only incidental investigation of disabilities. As a result, the criteria available by which women can be deemed disabled are very narrow and work-related, pertaining only to women between the ages of 18 and 64 who did not work because of a disability or whose labor force participation in the past year has been limited by disability or illness and who also receive Social Security or Supplemental Security Income. The Census Bureau does not claim to be able to measure disability from the Current Population Survey; rather, the inference of disability from these data was carried out by Decision Demographics, in consultation with authors of the *Report Card*.
- ¹³ Correspondence from Stephen J. Tordella, President, Decision Demographics, September 2001.
- ¹⁴ Health Care Fairness Act, as codified in 42 U.S.C. §287c-31 *et seq.*
- ¹⁵ National Institutes of Health, Office of Research on Women's Health, *Strategic Plan to Address Health Disparities Among Diverse Populations of Women* (undated) [Online]; Available: WWW URL: <http://www4.od.nih.gov/orwh/disparities-plan-new.pdf>, accessed 24 October 2001. Underscoring this need for better data collection, the Commonwealth Fund recently undertook a study of federal statutes, regulations, policies and procedures of federal agencies (primarily within the Department of Health and Human Services) that collect health data by race, ethnicity and primary language to determine the standards and reporting methods used by the agencies. Researchers found that while existing policies reflect the need for and importance of racial and ethnic data, laws, policies and practices for collection are often unclear and inconsistent. The Commonwealth's report recommends that HHS revise its standards and policies to address these inconsistencies and ensure the standards are followed by the agencies that implement them. Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (New York: Commonwealth Fund, Inc., 2001).
- ¹⁶ Behavioral, Social, Mental Health, and Substance Abuse Research with Diverse Populations. PA Number PA-01-096 (May 21, 2001) (sponsored by: National Institute on Mental Health, National Institute on Drug Abuse, National Institute of Child Health and Human Development, Office of Behavioral and Social Sciences Research, Office of Research on Women's Health)[Online]; Available: WWW URL: <http://grants.nih.gov/grants/guide/pa-files/PA-01-096.html>, accessed 24 October 2001.

- ¹⁷ Gay and Lesbian Medical Association and others, *Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health* (San Francisco: Gay and Lesbian Medical Association, 2001), 5. See also “Lesbian Health,” *Health & Sexuality* 6 (Washington, D.C.: Association of Reproductive Health Professionals, 2001) [Online]; Available: WWW URL: <http://www.ahrp.org>, accessed 19 October 2001.
- ¹⁸ Institute of Medicine. *Exploring the Biological Contributions to Human Health: Does Sex Matter?* (Washington, D.C.: National Academy of Sciences, 2001); Office of Research on Women’s Health, *ORWH FY2001 Research Priorities* (Washington, D.C. ORWH, 2001) [Online]; Available: WWW URL: <http://www4.od.nih.gov/orwh/FY01Respriorities.html>, accessed 10 October 2001.
- ¹⁹ Data on inclusion are published in National Institutes of Health, Office of Research on Women’s Health, *Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities as Subjects in Clinical Research: Comprehensive Report (Fiscal Year 1997 & 1998 Tracking Data)*(September 2000)[Online]; Available: WWW URL:[http: www4.od.nih.gov/orwh/fy97-98trkg.pdf](http://www4.od.nih.gov/orwh/fy97-98trkg.pdf), accessed 24 October 2001.
- ²⁰ U.S. General Accounting Office, *Women’s Health: Women Sufficiently Represented in New Drug Testing, but FDA Oversight Needs Improvement* (Washington, D.C.: U.S. General Accounting Office, 2001), GAO-01-754.
- ²¹ U.S. General Accounting Office, *Women’s Health: Women Sufficiently Represented in New Drug Testing, but FDA Oversight Needs Improvement* (Washington, D.C.: U.S. General Accounting Office, 2001), GAO-01-754. This report also indicates that there are difficulties in getting a full picture on the participation of women in clinical trials due to problems with efforts to monitor clinical trails related to participation, including missing data on sex and gender in reports from trials. Another GAO report released earlier in the year demonstrates the importance of women in clinical trials and an emphasis on understanding sex differences. The study found that most drugs withdrawn from the market in recent years had greater health risks for women than for men. U.S. General Accounting Office, *Drug Safety: Most Drugs Withdrawn in Recent Years Had Greater Health Risks for Women* (Washington, D.C.: U.S. General Accounting Office, 2001), GAO-01-286R.
- ²² U.S. Department of Health and Human Services, *Healthy People 2010 2nd ed.* (Washington, D.C.: U.S. Government Printing Office, 2000), 24-51 (leading health indicators reflect major public health concerns in the United States, chosen based on ability to motivate action, availability of data to measure program, and their relevance as broad public health issues).
- ²³ E-mail correspondence from Suzanne G. Haynes, Ph.D., Senior Advisor for Science, Office on Women’s Health, U.S. Department of Health and Human Services, September 2001.
- ²⁴ Another critical challenge is conducting appropriate comparisons among different points in time when there are adjustments in the data system (e.g., age adjustments and changes in classifications of diagnoses and health conditions). Most significant are the changes between Healthy People 2000 and 2010, with Healthy People 2000 age-adjusting to the 1940 standard for mortality, but not for other objectives. Healthy People 2010 objectives use the new 2000 population standard for mortality as well as most of the other population-based objectives. Specifically, while the change in the population standard from 1940 to 2000 for mortality data may be a better standard to use, there are major ramifications for trending that result. This *Report Card* has included mortality data age-adjusted to the 1940 population to make comparisons to the 2000 *Report Card*. In addition, NCHS has published morbidity and risk behavior data from BRFSS by state, sex, race/ethnicity, and age using the 2000 population standard as well. BRFSS Summary Prevalence Reports continue to report unadjusted data, however BRFSS will provide data tables online for the leading health indicators age-adjusted to the new population standard. Other changes such as the shift in the codes used for diagnoses from ICD-9 to ICD-10 codes as well as changes in how racial data are collected will also make it difficult to examine the changes in state performance for future *Report Cards*.
- ²⁵ Institute of Medicine, Committee on the Changing Market, Managed Care, and the Future Viability of Safety Net Providers, *America’s Health Care Safety Net: Intact but Endangered* (Washington, D.C.: National Academy Press, 2000), 8-10.
- ²⁶ One 2001 paper that may shed additional light on important issues related to access to quality long-term is Charlene Harrington, “State Minimum Nurse Staffing Standards for Nursing Facilities” (unpublished, available from the author, Chas@itsa.ucsf.edu, April 2001).
- ²⁷ L. Kohn and others, eds., Institute of Medicine Commission on Quality of Health Care in America, *To Err is Human: Building a Safer Health System* (Washington, D.C.: National Academy Press, 1999); Traves Crabtree and others, “Gender-Dependent Differences in Outcomes After the Treatment of Infection Hospitalized Patients,” *Journal of the American Medical Association* 282 (8 December 1999), 2143-2148 (women appear to be at increased risk for death from hospital-acquired pneumonia, even after controlling for other factors).
- ²⁸ Agency for Healthcare Research and Quality, *Making Health Care Safer: A Critical Analysis of Patient Safety Practices: Summary* (Rockville, AHRQ Publication No. 01-E057 July 2001)[Online]; Available: WWW URL: <http://www.ahrq.gov/clinic/ptsafety/summary.htm>, accessed 10 October 2001. See also U.S. Department of Health and Human Services, “HHS Announces \$50 Million Investment to Improve Patient Safety,” *Press Release* (11 October 2001)[Online]; Available: WWW URL: <http://www.ahrq.gov/news/press/pr2001/patsafpr.htm>, accessed 9 November 2001.
- ²⁹ Agency for Healthcare Research and Quality, “AHRQ Women’s Health Highlights: Alternative Medicine” (October 2000) [Online]; Available: WWW URL: <http://www.ahrq.gov/research/womenh3.htm#altern>, accessed 11 October 2001. Evidence-based analyses are conducted on existing research to identify research that supports various approaches and assesses the strength of the evidence for those approaches.
- ³⁰ Agency for Healthcare Research and Quality, “AHRQ Women’s Health Highlights: Alternative Medicine” (October 2000) [Online]; Available: WWW URL: <http://www.ahrq.gov/research/womenh3.htm#altern>, accessed 11 October 2001.
- ³¹ National Center for Complementary and Alternative Medicine, *Strategic Plan to Address Racial and Ethnic Health Disparities*, (Washington, D.C.: U.S. Department of Health and Human Services, 2001) [Online]; Available; WWW URL: http://nccam.nih.gov/strategic/health_disparities.htm, 10 October 2001.
- ³² The U.S. Preventive Services Task Force provides a resource that systematically reviews the effectiveness of various practices. The current edition for 2000-2002 and updates on new guidelines and effectiveness analyses are published in review journals to provide for more timely release of information. Agency for Healthcare Research and Quality, *Preventive Services* (Washington, D.C.: Department of Health and Human Services, 2001) [Online]; Available: WWW URL: <http://www.ahrq.gov/clinic/prevenix.htm>, accessed 10 October 2001.
- ³³ Substance Abuse and Mental Health Services Administration, *1999 National Household Survey on Drug Abuse State Tables of Model-Based Estimates* [Online]; Available: WWW URL: <http://www.samhsa.gov/oas/NHSDA/99StateTabs/toc.htm> accessed 13 October 2001.
- ³⁴ Correspondence with Professor Beth Glover Reed, Director, Policy Research on Women and Drugs (PROWD), University of Michigan, School of Social Work, 26 May 2000.

- ³⁵ National Center on Addiction and Substance Abuse of Columbia University, *Shoveling Up: The Impact of Substance Abuse on State Budgets* (New York: Columbia University, 2001) [Online]; Available: WWW URL: <http://www.aishealth.com/ManagedCare/BehavioralHealthCharts.html>, accessed 13 October 2001 (provides state-by-state analyses, including attention to special populations, but little emphasis on women); Tami Mark and others, "Spending on Mental Health and Substance Abuse Treatment, 1987-1997," *Health Affairs* (July/August 2000), 108-120; Cynthia Dailard and Elizabeth Nash, "State Responses to Substance Abuse Among Pregnant Women," *The Guttmacher Report on Public Policy* (December 2000), 3-6 (state-by-state analysis of laws pertaining to pregnant women who use drugs); U.S. Center for Substance Abuse Treatment, *Changing the Conversation: The National Treatment Plan Initiative to Improve Substance Abuse Treatment* (December 2000) [Online]; Available URL: <http://natxplan.org>, accessed 13 October 2001.
- ³⁶ The SEER program provides an annual series of reports based on their monitoring efforts of ten percent of the U.S. population. It provides cancer incidence rates, mortality rates and five-year estimates of survival that are developed from various sources including the SEER program itself and the National Center for Health Statistics. More details are provided at <http://cis.nci.nih.gov> and <http://seer.cancer.gov/>.
- ³⁷ The Region VIII Women's/Minority Health Database is another example of morbidity data available within states but not consistently collected across all states. U.S. Department of Health and Human Services, Public Health Service, *Region VIII Women's and Minority Health Database* (Denver: Department of Health and Human Services, 2001). This CD-Rom contains a variety of data sources at the state and when available, county-level data.
- ³⁸ "Building Data Systems for Monitoring and Responding to Violence Against Women," *Morbidity and Mortality Weekly Report* 49 (27 October 2000), 1-18.
- ³⁹ U.S. Department of Health and Human Services, *Oral Health in America: A Report of the Surgeon General* (Rockville: U.S. Department of Health and Human Services, 2000), 77-78.
- ⁴⁰ U.S. Department of Health and Human Services, *Oral Health in America: A Report of the Surgeon General* (Rockville: U.S. Department of Health and Human Services, 2000), 88.
- ⁴¹ The *Report Card* now has a status indicator addressing oral health. For useful state-by-state analysis of policy initiatives on oral health, see *Missing the Mark: Oral Health in America* (Chicago: The Oral Health America National Grading Project, 2000); Jane Perkins and Justin Short (National Health Law Program), *State Initiatives to Improve Dental Care* (Updated June 2001) [Online]; Available: WWW URL: <http://healthlaw.org/pubs/200102dentalmemo.new.shtml>, accessed 5 October 2001.

